FAMILIES WITH MENTALLY HANDICAPPED CHILDREN: STUDIES IN THE PASTORAL METHOD

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C O N T E N T S

INTRODUCTION

The research project reported in Chapter 4 of this thesis was made possible by a grant from the Scottish Home and Health Department, Research and Intelligence Unit. At the same time, the writer was serving as assistant chaplain at Gogarburn Hospital, becoming a member of the team serving hospitals in the Royal Edinburgh Group and receiving a nominal stipend in respect of his chaplaincy services.

A Liaison Committee was set up to sponsor the survey of parental attitudes, needs and experiences. It comprised representatives from Edinburgh and West Lothian medical, educational and social work departments, nominees from three voluntary societies, and a chaplain colleague representing the Church of Scotland Home Board. This committee met a total of six times, receiving progress reports and contributing to the recommendations in their final form.

As Chaplain at Gogarburn the writer shared fully in the ongoing life of the hospital; he joined various teams within the hospital, made himself available to residents, relatives and staff, conducted worship, worked with the hospital's voluntary society, recruited volunteers from local churches, addressed neighbouring church groups and ministers' fraternals, and so on.

This dual responsibility - to the hospital population and to the families interviewed - whilst arduous was also advantageous. The writer in his preceding eight years as a minister had not encountered or appreciated the dimensions of the problem, and thus identified with the low level of knowledge and concern demonstrated by the average minister and congregation. By mixing with the mentally handicapped in the hospital and sensing the disappointment and

social isolation of many of the residents, he was better able to evaluate similar feelings expressed by the parents he interviewed. Because he sensed in himself the equal and opposite dangers of arid intellectualism and ungoverned sentimentality, the writer became adept at sifting the wheat from the chaff in the articles and books consulted. Over the two years, also, he began to realise that his own attraction towards the mentally handicapped was dependent on two factors; first, that he was a member of a team caring for them, and secondly, that he could go off duty with a clear conscience because the mentally handicapped were not his offspring. Any tendencies towards harsh judgments on parents who seemed rejecting or embittered were nipped in the bud as this realisation dawned on him.

The foregoing relates to the feeling awareness brought by the writer to the interviews reported in Chapter 4. The methodology adopted in the survey is discussed at some length in that chapter. As to the remaining chapters, one or two comments are in order about the choice of material. Any historical data emanating from before the nineteenth century is perforce scarce and vague, and the researcher from whatever background is reduced to inspired guesswork. The proliferation of medical, educational and social work theories and practices since then has not been matched by theological or pastoral activity. Writing from a theological perspective, therefore, one has had to rely on a handful of Catholic writers and draw heavily on the rich deposits of Protestantism - American in origin. The paucity of indigenous Christian literature is part cause and part effect of the regrettable state of affairs. It is, moreover, a matter of reget that articles outnumber books by an astronomical margin; the books remain to be written.

ACKNOWLEDGEMENTS

We are grateful to the following people for professional advice and personal encouragement at various stages in the undertaking:- Professor J. C. Blackie (New College) and Dr. A. D. Forrest (Gogarburn Hospital) had the vision to begin with, made possible the joint researcher-chaplain role, and offered amply and gladly their time, experience and guidance throughout the project; Dr. Rebecca Wood (Miami, Florida) assisted in the conduct of the interviews and her skills as psychologist and parent-counsellor greatly enhanced the validity of the exercise; administrative staff at Gogarburn Hospital performed many necessary and unsung tasks with goodwill and humour; Mr. Ken Birchall guided us through the labyrinthine maze of computer programming at the South East Regional Hospital Board offices; Dr. John Clarke gave such good and clear advice on statistics that we learned to fill our waking hours for several months with Chi square tests - and not lose heart; Anne Day typed the draft of Chapter 4 and the final form of Chapters 1 - 3 with skill; the library staffs at New College and the Royal Edinburgh Hospital met inexcusable demands by 'phone and in person with unfailing courtesy and efficiency; Rev. Murray Leishman and Miss Charlotte Clunie, chaplain colleagues, shared the workload at Gogarburn throughout and increasingly encouraged us to devote our time in the second year to writing the thesis; without the co-operation of one hundred and forty four families in Edinburgh and West Lothian nothing could have been accomplished; neighbours befriended a thesis widow and orphans to whom the writer pays final tribute and promises now to return to normal.

ABSTRACT OF THESIS

This thesis seeks to determine the attitudes, experiences and needs of families with a mentally handicapped child and relate these to the ministry of the church. The first chapter reviews social and ecclesiastical attitudes and treatments prior to the nineteenth century. Viewed either as wicked and beyond redemption or as innocent and not needing redemption by the church, the mentally handicapped were often exorcised and excommunicated, avoided and abandoned, or sheltered and deprived along with the mentally ill, paupers and criminals. Protestantism, with its stress on rationality as essential to faith and its appeal to fulfil one's election by working for others, inadvertently worked against the mentally handicapped.

The second chapter outlines the contribution made by early educational pioneers, many of them Christian. Doctors began to take the condition seriously; but neither teachers nor doctors could effect a cure. Alarmist policies were perpretrated by the eugenicists which resulted in the building of large, remote asylums and a total detachment of public interest and concern. Community care for the mentally handicapped became a clarion call, possibly as a result of the permissive society leaving room for nonconformists. A definition of the two forms, pathological and subcultural, of mental handicap is given and an estimate of its prevalence.

The third chapter reviews the different approaches towards working with the families of mentally handicapped children taken in Britain and elsewhere. The British approach has been to blame the quality of the services as the reason for parental complaints, the American has been to counsel the parents as if the blame lay in their neurotic reaction to an insoluble condition. Many articles are reviewed

and a plea entered for the implementation of an approach in this country which combines the strengths of both viewpoints.

The fourth chapter records in details the responses of 144 families with a mentally handicapped child in Edinburgh and West Lothian to a 100 item questionnaire. The data covers the child, the family, parents' past reactions and experiences, present situation and needs met, and parental estimates of coping together with hopes and fears for the future. Hundreds of tables and pages of verbatims lead to a discussion of the significance of social class in all the ramifications of mental handicap, and recommendations for the improvement of the diagnostic interview, domiciliary services, professional-parent communications, and a programme designed to ameliorate the lot of the culturally handicapped mother and child.

The last chapter reviews the religious needs of the mentally handicapped and their parents. The mentally handicapped need the right to live, to live in the family circle wherever possible, to live in the mainstream of society, and to live as fully as possible within the membership of the Christian church. Their parents need help with guilt and disappointment, long term supportive relationships, and the realisation that the church couples deeds with words on behalf of the mentally handicapped who cannot plead for themselves. A few recommendations of a practical nature are made, and topics for future research are directed especially at the Protestant churches.

Chapter 1 A survey of the attitudes towards and treatment of the mentally handicapped prior to the nineteenth century

> The casual observer may be forgiven for feeling puzzled at the groping of men and women deservedly acknowledged as experts. It does indeed seem strange that after nearly a century of scientific occupation with 'feeble-mindedness' those best informed should still be wondering what they have been, and are, dealing with.(1)

We assume that mental deficiency has existed as long as man. It has only become a separate discipline within the last one hundred and fifty years. In earlier times it was confused with mental illness and for millenia mental illness was identified with demon possession. Our survey, then, has to tread the tightrope between too little specific and too much marginal evidence. We propose to examine the data from pre-Christian times and within the Christian era on either side of the Reformation by concentrating on the specific references and touching on the broader issues. Two strands intertwine and separate constantly in the attitudes and treatments of society and the church; and parents unavoidably experienced at first hand the tensions articulated by the larger institutions. On the one hand the mentally handicapped are feared, blamed and corrected; this approach meeting with little or no success, they are finally punished or destroyed. On the other hand the mentally handicapped are pitied, accepted and appreciated; this approach failing to win over the majority of people, they are finally protected or hidden. The first approach challenges the masculinity of society which vows to do something to the wicked offenders; the second evokes the femininity of society which warms to what the weak innocents do to it.

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(1) Leo Kanner, 1948, Feeble-mindedness: absolute, relative and apparent, The Nervous Child, 7. 365-397; quoted in D.D. and B.M. Braginsky, 1971, Hansels and Gretels, 1. We deliberately quote Kanner anachronistically (he refers to mid 19th - mid 20th centuries).

These two lines converge in treating the mentally handicapped as dependent - even as perpetual - children. They are denied any responsibility, either because it had generously been offered to them and not utilised, or because it had wisely been kept from them. We may detect the same phenomenon in the church's ambivalence with respect to the sacraments. All such can be saved by means of baptism, few or none such can grow by means of the eucharist. Until the period we are to review in the second chapter, it must be admitted that the tension between the two approaches served more to alienate the respective proponents than ensure a synthesis beneficial to the mentally handicapped.

A Pre-Christian Era

> There is a reference in the Ayurdeva some 1400 years before the birth of Christ where possession by demons is described as the cause of insanity. Seven demons were listed. One of these rejoiced in the name of Pisaka and the characteristics of this gentleman were that he was gluttonous, dirty, without memory, restless, uneasy, walked naked and tore his flesh.(2)

There are a few references in the literature of antiquity to idiots, imbeciles and fools. The word idiot comes from the Greek "idiotes" meaning "a person who cannot take part in public life and cannot carry on a conversation". Imbecile probably had its origin in "bacillum" a short stick, without whose aid an imbecile or weakling could not stand unaided. The concept of weakness grew to include moral weakness, for instance dishonesty, and imbecile acquired the cognate, embezzle. Fool comes from the Latin "follis", a pair of bellows, and was descriptive either of his puffed cheeks or his likeness to a windbag. Moron is a straight transliteration of the Greek "morōn", foolish, with arrested intellectual development.

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(2) Ronald C MacGillivray, 1962, Mental Deficiency, Retrospect and Prospect, 3

In Sparta the city fathers and in India specially appointed functionaries examined all new born infants and ordered all those born with signal defect to be destroyed (3). Pericles recorded that in Greece defectives were abandoned on mountains or drowned in rivers, Cicero claiming that his countrymen in many parts of the Roman Empire did likewise (4). Had this been universally practised, of course, we should have no such persons alive. For two possible reasons many defectives survived. First, their defect was not apparent at birth, i.e. they were mildly handicapped, fools rather than idiots. Secondly, the aristocrats needed diverting and idiots and fools alike helped provide amusement cheaply and permanently if they were kept as household pets, court jesters or seers and seeresses.

Marcus Aurelius Martialis described defectives as having narrow heads and long ears which they moved in the manner of asses. He referred to the fame of Gabba in Augusta's court (5), and elsewhere complained to his friend Gargilianus that having bought an idiot for 20,000 sesterces he wanted his money back as the purchase proved not to be a genuine "morio". Seneca (6) in recording the death of his wife's "fatua" (defective) Herpaste, used this as a platform for a philosophical reflection not at all related to her lifetime's follies or mourned death.

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(3) ibid., 3

(4) Charles G Chakerian, 1966, The community, the church and the mentally retarded, 5

(5) Martialis, Epigrammata X, 101; quoted in Leo Kanner, 1964, A history of the care and study of the mentally retarded, 4

(6) Seneca, Ep. to Lucretius 50; quoted ibid., 4

The Old Testament refers often to madness but nowhere in an unambiguous manner to idiocy, for precisely the reason Harrison states:-

> Among primitive races disease was either regarded as the result of hostile magic gaining a hold upon a person, or else its incidence was ascribed to the violation of a taboo. In either event, a background of magic, sorcery and witchcraft was presupposed... (such people were left well alone for) they were regarded as having a peculiar relationship with a possessing spirit or demon.(7)

When law and religion combine to outlaw certain people (e.g. Exodus 22:18 You shall not permit a sorceress to live; Leviticus 20:27 A man or a woman who is a medium or a wizard shall be put to death...) it would be unrealistic to expect that society to indulge in differential diagnoses of the progenitors or victims in question. For the Hebrews fool, folly and foolishness have an ethical rather than rational connotation. Whether he displays the brutish, subhuman mentality ("baar") of Psalm 73:22, the simplicity through ignorance ("pethi") of Proverbs 9:6 or the less innocent folly ("nabal") of II Samuel 13:13, the fool is culpable, and held to be evil for succumbing to the blandishments of Folly (8). In a word, the fool is impotent in face of the knowledge of good and evil, beset with a fundamental defect in his will.

The Koran may be referring to lunatics or idiots in its injunction "Give not unto those who are weak of understanding the substance which Allah hath appointed you to preserve for them; but maintain them thereout and clothe them and speak kindly unto them". (9)

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(7) R. K. Harrison, 1962, Disease, I.D.B., I, 847, 850-851

(8) S. H. Blank, 1962, Folly, I.D.B., II, 303-304

(9) MacGillivray, op. cit., 3-4

It strikes one of the first blows for compassion in the period under review (which has clearly stretched to include non Christian religions of the Christian era). In the same vein is the comment by Adler (10), "Jewish religious law requires strict consideration and good care of the mentally deficient".

As so often, the Greeks made the significant advances in knowledge which in turn shaped attitudes and treatments. Hippocrates refused to accept the appellation "sacred disease" given to epilepsy. "It has a natural cause just as other diseases have. Men think it is divine only because they do not understand it"(11). He proposed the humoural theory in which four substances, blood, phlegm, choler and melancholer were in quantitative balance and functional interaction in the healthy person, but a preponderance of one or more of these bodily substances gave rise to characteristic diseases and personality changes in the unhealthy person. Furthermore, he identified the brain as the organ of the mind, an insight which Plato alone of his immediate successors developed. Plato argued that the rational parts (located in the brain) and the irrational parts (scattered throughout other bodily organs) of man's soul could come into conflict and that the higher by submerging the lower could cause madness. Sadly, however, Plato resuscitated an idea Hippocrates had sought to destroy, viz. that madness could be sacred or profane (12).

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(10) Helmut E Adler, 1972, psychology, Encyclopaedia Judaica, XIII, 1343, citing Sha'agat Aryeh Y.D. 240:10 and E.H. 119:6

(11) Hippocrates; quoted in Leslie D Weatherhead, 1952, Psychology Religion and Healing, 30-31

(12) David Stafford-Clark, 1963 (2nd edn), Psychiatry Today, 17-19

The Babylonians and Egyptians practised trepanning (boring holes in the skull of the victim) as a means of aiding the escape of the possessing demon when the shaman correctly identified and exorcised him. Insofar as certain defective persons manifested symptoms and mannerisms common in the insane, e.g. foaming, twitching, ungainliness of gait, crazy utterances, mutism, violent mood swings, etc., the chances rise that they were victims of society's punitive measures. Stafford-Clark paints a picture in softer colours, than the sombre hues of the scant evidence we have assembled, when he concludes:-

> The fate of those of undeveloped or defective intelligence was apt to be less severe; they were either ignored or treated with some of the indulgence but by no means all of the affection, commonly displayed towards children. They were the harmless natural idiots, the simpletons, neither inspired nor accursed. When they died it was from neglect rather than persecution as a rule.(13)

There is insufficient documentary evidence to make it possible or sensible to decide whether his 'soft' judgment or our 'hard' judgment is nearer the truth. In either event the mentally defective were appallingly treated, their parents almost certainly blamed and ostracised, their guardians cynical and the public unconcerned.

It is a possibility, and no more, that the mentally handicapped who were not slain at birth or starved in their mountain hideouts benefited from the ancient and universal custom of hospitality. For the Hebrews there was a theological interpretation and motivation for this virtue. In Deuteronomy Israel is urged to recall YHWH's choice of her, His love and faithfulness, His saving

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(13) ibid., 14

intervention in the exodus, His guidance and provision in the desert, His planting of her in an abundantly endowed land; and she is urged to be loyal loving and exclusive in her devotion to YHWH, obedient to His commandments, and warm hearted and generous in her dealings with her neighbours. (14) In a word, as YHWH had dealt with them when they were weak and helpless in a strange land, so must they deal with the weak and helpless in their midst. Once a recipient, now and always Israel must be a channel of YHWH's compassion. Each had his part to play in the divine economy of YHWH's dealings with Israel, and the sojourners, fatherless and widows who received the harvest gleanings (Deuteronomy 24: 17-22) may also have included the idiots. Everyone who called forth pity and practical help deserved a benediction, and the Hebrew Prayer Book records one such on meeting a strangely formed creature such as a giant or a dwarf; "Blessed art Thou, O Lord our God, King of the universe, who variest the forms of Thy creatures" (15).

We believe that the "ger" or stranger who settled as a sojourner may have served as a model for the mentally handicapped in that he was expected to conform as far as possible to the covenant regulations in return for his protection as a weak and disinherited subject (16). This remains conjecture, but what is certain is that for the Hebrew the ultimate fate was not having a community to belong to, rather than the abstract consideration of not having a personal relationship with your deity. The fear of the stranger was gradually replaced by pity for him. Concluding a

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(14) R. S. Driver, 1902, I.C.C. Deuteronomy, xix

(15) Quoted in Victor Gollancz, 1950, A Year of Grace, 62

(16) T. M. Mauch, 1962, Sojourner, I.D.B., IV, 397-399

wide-ranging review Hamilton-Grierson writes:-

> The interests of the community were served better by preserving and protecting the stranger than by killing him... In time this applied to the 'useless' stranger, e.g. the beggar, the weakling and the wanderer. Eventually the stranger, once his face became familiar, his presence welcome, became himself the subject of rights. (17)

Our attempts to soften the harsh realities to which the hard evidence attests represent a reaction perhaps known to parents of defectives in those times. Such parents, must have shrunk from the practices of avoidance, abandonment and extermination on the one hand, and of protection by idle aristocrats or large families requiring amusement from captive idiots on the other hand. We would like to believe that some men saw them as "les enfants du bon Dieu", or as "sancta simplicitas" as occasions for which the normal both praised God for His goodness to them and practised kindness to the weak and innocent. However, this must remain a hypothesis for which no evidence can be adduced. Nevertheless, every age has had its "scurrae" or "moriones" who have used their power or weakness as a means of livelihood, who have carved out a life for themselves in spite of prevailing attitudes and treatments. Such a one was Fatua, the famed seeress, whose prophecies, nonetheless, drove her listeners "fatuus", i.e. out of their mind, as Kanner writes.

B Pre-Reformation Christendom

> Moneyles thei walke
> With a good wil, witlees, meny wyde contreys
> Ryghte as Peter dude, and Paul, save that thei preche nat
> ⋮
> Mattheu ous techeth
> We sholde have hem to house, and help hem when thei come (18)

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(17) P.J. Hamilton Grierson, 1920, Stranger, E.R.E., XI, 895-896

(18) William Langland, 1362, Piers Plowman; quoted in Kathleen Jones, 1955, Lunacy, Law and Conscience, 2-3

We have noted that demon possession as an umbrella term marked the full extent of most nations' etiology of disease. As a Jew, Jesus was predictably accused by his countrymen of "having a demon" (with its serious rider that "he should not be heard") for how else but by sorcery and witchcraft, by being himself one of the accursed, could he cast out demons and restore faculties to those deprived of them? Jesus retorted "I have no demon but I fear my Father" (St. John 8:48-49) and it was by invoking the name not of a similar but superior spirit, but of God Himself, that he ordered the demons to recognise his identity, acknowledge his supremacy and vacate the afflicted person. Into this vacuum the spirit of God must come lest seven devils worse than the first re-possess the person (St. Luke 11:24-26). So Jesus could approach with confidence and compassion the epileptic boy (St. Matthew 17:14-18 where the word used means "moonstruck" and where the boy was probably a low grade moron, according to Harrison (19)) and the Gadarene madman (St. Mark 9:25). In view of the widespread practice of exorcism "in the name of the Father, Son and Holy Spirit" it is salutary to mention Gaster's observation that :-

> the verb "exorkizein" (exorcise) i.e. expel by conjuration, is itself nowhere employed in the New Testament to describe Jesus's casting out of demons; and the corresponding noun ("exorkistai") is applied only in an opprobious sense to certain itinerant shamans who attempted to do so by invoking his name (Acts 19:13). (20)

The ingrained Jewish resistence towards demons, even for the purpose of exorcising them, seems to have coloured the early church's thought forms, although in practice it rapidly went over

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(19) R. K. Harrison, 1962, Epilepsy, I.D.B., II, 123

(20) T. H. Gaster, 1962, Demon, I.D.B., I, 823

to full scale commitment to exorcism.

In far more cases than these, however, Jesus operated on the assumption that "the existence of sickness in this world belongs to the character of 'aiōn houtos' of which Satan is the prince" (21). Jesus did not draw a necessary connection between sin and suffering, He did appeal for faith and offer forgiveness in many instances, He did not question the widespread belief in demons, and He included in His concern (as members of God's kingdom, by right) the deprived and depraved, old and young, men and women, simpletons and sages, Jew and Gentile. Unable to discover precisely His attitude towards the mentally handicapped, we surmise that He would have been moved with pity over those even He could not change and accepted as they were the simpletons (to whom, or those sharing some of their characteristics, God revealed truths hidden from the wise, St. Matthew 11:25). Nowhere can we trace in His ministry any marks of intolerance, persecution and cruelty such as disfigured the church's record of dealing with the mentally ill - and in many cases, mentally handicapped.

A classic statement of the church's preoccupation with demons and their angelic counterparts can be found in the Fourth Lateran Council of 1215:-

> God is the creator of all things visible and invisible, spiritual and corporeal, who of his own omnipotent power ... created the devil and other demons good, but they became bad of their own accord. Man sinned by suggestion of the devil. (22)

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(21) W. Foerster, 1964, Daimōn, T.D.N.T., II, 18-19

(22) H. L. Pass, 1920, Demons and Spirits in Christianity, E.R.E., IV, 565ff. This is a comprehensive article with evidence, stretching from the Shepherd of Hermas up to Calvin, of the church's fascination with a formerly taboo doctrine.

This represented the only safe course open to the Christian between the Scylla of ascribing disease to the work of the deity and the Charbydis of making disease accidental, independent of divine control and thereby impugning divine omnipotence. The uneasiness with which the church viewed this situation can be gauged by the violence and vileness of the Malleus Maleficarum, The Hammer of the Witches. Heinrich Kramer and James Sprenger, two Dominican teachers, produced this monumental tome in 1486 in response to the bull issued by Pope Innocent VIII in 1484 that the world should be purged of an invasion by witches, succubi, incubi and the like. This three part work first pronounced that witches and witchcraft existed and to deny this was heresy, then described the types of witches and how they might be recognised, and finally detailed the treatments suitable for those convicted of witchcraft. It must be doubted whether any product of the human mind has had such a lasting hold, bitten so deep or issued in such inhumanities as this work from the late Middle Ages. Tillich claims that the "church of this period lived in a constant anxiety about the presence of the demonic within itself and others". (23). In the earlier Middle Ages (ca. 1000-1300) the church celebrated the power of the divine in conquering the power of the demonic in daily life. This decline in confidence may be yet another of the factors thrusting up powerfully to surface in the Reformation.

Although witches were first persecuted in Europe around the year 430, and legislation for the repeal of their summary execution was not passed in Britain until 1736 (24), persecution was very much a

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(23) Paul Tillich, 1968, A History of Christian Thought, 148

(24) Stafford-Clark, op. cit., 29, 34

last ditch measure by the church. The first move was exorcism. McNeill writes (25), "by the time of Cyprian (256) the exorcist - a minor order of ministry - was presented at his ordination with a manual containing formulae." An early Latin missal describes the exorcism of baptismal candidates:-

> The exorcist places his hands upon the head of the prostrate catechumen and pronounces a long adjuration. The God of Abraham, Isaac, Jacob and Moses is invoked to send an angel; the cursed devil is commanded to bow before divine judgment, acknowledge God and Christ, and flee from the servants of God about to be baptized; the sign of the cross on the candidate's forehead becomes the talisman which the demon will never dare to violate. (26)

As infant baptism began to supersede the initiation of adult converts the office of exorcist became otiose, its functions performed by the priest. Clebsch and Jaekle also quote examples of how the church anointed all bodily orifices to repulse demonic onslaughts (27) and poured water from the skull of a suicide down the throat of an epileptic in the hope that the latter's demons would taste destruction and depart hastily (28).

Minds of the calibre of Aquinas and Bonaventure grappled with the problem of squaring divine justice with the radical freedom of human will in the demon possessed. The entrance of the demon into the human body, they argued, allowed it to control the physical faculties, but the demon could not enter the soul, which remains free, though its functions in respect of the body it informs were suspended. Estius likened the demon-possessed to a vessel being

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(25) J.T. McNeill, 1953, An historical survey: religious healing of soul and body, 49 IN Paul B. Maves, The Church and Mental Health

(26) L. Duchesne, 1931, Christian Worship: Its Origin and Evolution, 299-300; quoted in William A Clebsch and Charles R Jaekle, 1967, Pastoral Care in Historical Perspective, 38

(27) Clebsch and Jaekle, op. cit., 34-35 (28) ibid., 40

steered by a pilot rather than its captain. In the following fairly typical scholastic definition more anxiety is expressed about the untarnished purity of doctrine than about the welfare of the afflicted person:-

> Demons in the individuals whom they possess are like motors within the bodies which they move but in such a way that they impress no quality on the human body nor do they give it any mode of existence, nor strictly speaking, do theyfconstitute together with the possessed person, a single being. (29).

Voices were raised in protest against the prevailing philosophy and practice; Soranus in the first century used light, warmth, music and bath-ing as materia medica for his deranged patients; Paracelsus in the mid-16th century wrote "mental diseases have nothing to do with evil spirits or devils ... one should not study how to exorcise the devil but rather how to cure the insane ... the insane and the sick are our brothers" (30); Avicenna in the early 11th century distinguished amentia/fatuity from other forms of mental disorder,holding it to be caused by a cold humour occupying the body of the middle ventricle (31). Nevertheless the church carried the day. Those persons who had not been successfully exorcised in baptism, those who were guilty of witchcraft and those of their victims who did not respond to exorcism as a separate activity when adults, were alike excommunicated and denied Christian burial. The only room that was left for defectives was in illustrated manuscripts, where fools were depicted in association with the capital letter D, from the first word of Psalm 53, "Dixit insipiens in corde suo non est Deus" (The foolish body has said in

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(29) Benedict XIV, De servorum Dei beatificatione et beatorum canonisatione, 4.1.29.2; quoted in L.J. Elmer, 1967, Diabolical Possession, N.C.E., IV, 839-840

(30) Stafford-Clark, op. cit., 30

(31) MacGillivray, op. cit., 4

his heart, there is no God) (32).

Kramer and Sprenger (33) summarise this whole sorry chapter in the church's dealings with the mentally ill-cum-handicapped with their assertion "We have indeed the authority of the whole of scriptural teaching that God allows the devil to afflict sinners more than the just". We interpret this development as a logical continuation of the earlier practice of avoidance, abandonment or extermination with the rider that the church and society were at least trying to come to grips with the problem. The threat it posed to society's welfare, the brake it put on the church's progress towards making all conform to the rule of faith, the very intractability of the condition combined in the end to make the conclusion inevitable that mental and moral defect were one and the same thing. To an age increasingly enamoured of reason a rational God could not have planned such irrational, incalculable people as the defectives, and the church was obliged in the name of this rational God to apply any and every means to rid the demon-possessed of their demons, which failing, the world of the demon-possessed.

Is there any evidence that the mentally handicapped in the Christian era did benefit from hospitality? To remove hospitality from the gospels would be impossible; the spread of the church in the early missionary journeys leaned heavily on this practice. New converts were asked to recall the exile in Egypt, to entertain the stranger, who might be an angel unawares (Acts 4:11). It was thus

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(32) ibid., 4

(33) Kramer and Sprenger, op. cit., 169, (Eng. tr., Montague Summers); quoted in Clebsch and Jaekle, op. cit., 200

that converts were made (Acts 16:15, 33) and house churches established (Romans 16:4). Over and above all was the dominical word that in showing unconditional and unrestricted love for the "xenos" (stranger) one was entertaining Jesus Himself (St. Matthew 25:31-46). Ignatius insisted that Christ was present in the guests and hospitality thus became an expression of gratitude to Christ (34). As the office of deacon grew in importance there was added to its duty of collecting and distributing alms within the congregation of believers the new duty of "hospitalitas", the helping of any needy brethren in the name of the Christian community. By the middle of the third century Cornelius spoke of caring daily for 1500 widows and immigrants in Rome, while Chrysostom recorded a daily ministry in Constantinople to 3000 widows, foreigners and patients (35).

Hospitals existed from as early as 300 B.C. in Ireland, from 252 B.C. in India and even earlier in Greece (where temples to Asklepios were common and 'cures' were familiar as the devotees slept in the temple precincts), (36). The significant Christian contribution was the establishment of "xenodochia", inns for strangers. Originally these were solely for the rest and refreshment of those on a long journey or fulfilling some public responsibility but as time wore on they opened their doors to all in need. Together with infirmaries, foundling homes, orphanages and homes for the elderly they completed a network of church-run facilities catering for the needs of most citizens.

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(34) Ignatius, ad Ephes., 6.1; quoted in J van Paasson, 1967, Hospitality, N.C.E., VII, 154-155

(35) F. X. Murphy, 1967, Diaconia, N.C.E., IV, 840-841

(36) S. Weatherhead, op. cit., 28-29, 94 footnote

Tertullian could proudly claim in the days of persecution:-

> Our care for the derelict and our active love have become our distinctive sign before the enemy. 'See' they say, 'how they love one another and how ready they are to die for one another'. (37)

By the time Christianity had become the established religion this claim was even more realistic, for Constantine decreed in 325 at the Council of Nicaea that "in every city separate facilities are to be provided for pilgrims, the sick and the poor." (38). This was so diligently carried out that Julian the Apostate in 362 wrote testily to his pagan priest Arsacius:-

> Why do we not turn our eyes towards those institutions to which the impious religion of the Christian owes its growth, towards the help it gives to aliens? Build many xenodochia in every city. It is a shame that the inhuman Galileans sustain not only their poor but ours as well. (39)

Hospitals specifically for the mentally ill, and handicapped (?) were established in Hamburg in 1375 and in Mirandola in 1400 according to Scaduto (40).

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(37) Tertullian, Apol. 39; quoted in M. Scaduto, 1967, Works of Charity, N.C.E., III, 480-497

(38) Constantine, Canon 75; quoted in E. Nasalli-Rocca, 1967, History of Hospitals up to 1500, N.C.E., VII, 163-166. This is a most enlightening article, documenting fully the siting of hospitals, their staffing, the relationship between hospitals and monasteries and later cathedrals, the involvement of wealthy patrons and eventually guilds of merchants in the funding of hospitals, and the beginnings of secularisation.

(39) Julian, Ep. to Arsacius; quoted in Sozomen, Hist. eccl. 5. 15 quoted in Scaduto, op. cit., 485

(40) Scaduto, op. cit., 490. "Toward the end of the Middle Ages conditions for the care of the mentally ill, who until then had been treated as prisoners or worse, were greatly improved..." Scaduto from the Catholic and McNeill from the Protestant stance bemoan the Reformation's effect in divesting works of charity of their transcendent quality, focussing on the fellow citizen rather than the brother in Christ.

In the light of the foregoing, we believe it was quite likely that any defectives driven from their villages by guilt-ridden parents and fearful neighbours, eventually found their way to monastic houses brought there by that other band of wayfarers, the pilgrims. The Rule of St. Benedict laid down:-

> All guests are to be received as Christ himself; for He Himself said: 'I was a stranger and ye took me in' (St. Matthew 25:35). And to all fitting honour shall be shown; but most of all, to servants of the faith and to pilgrims. (41)

Others again could have been sheltered in the Priory Order of St. Mary of Bethlem, London, founded in 1247 to protect:-

> many men that ben fallyn owte of hyr wytte. And fulle honestely they ben kepte in that place; and sum ben restoryde unto hyr witte and helthe a-gayne. And sum ben a-bydyng there yn for evyr. for they ben falle soo moche oute of hem selfe that Hyt ys incureabylle unto man. (42)

To the retort, it is the mentally disordered rather than the mentally handicapped who are here in mind, we would recall Kanner's cautionary note (see page 1) and supplement Jones's admission (relating to the period as late as the mid-18th to mid-19th century) "the words insane and insanity are used in this survey in the 19th century sense which covered both classes, the mentally disordered and the mentally defective." (43). All inmates of Bedlam (as it became popularly known) would have undergone privation, exploitation and gross intimidation as Dainton makes clear when specifying the charges brought against the hospital's absentee chaplain. From 1388 the master of the hospital, one of

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(41) Rule of St. Benedict, LIII, 6th century; quoted in Henry Bettenson, 1959, Documents of the Christian Church, 173

(42) Gregory, 1451, Historical Collections; quoted in Rotha M Clay, 1966, The Medieval Hospitals of England, 33

(43) Jones, op. cit., x

the king's chaplains had cared nothing for the wellbeing of the patients and had not visited the establishment. He had made a legal agreement with Peter Taverner, the hospital janitor, assigning to him "the safe keeping of the poor and sick as well as the custody of the alms." (44). The aforesaid chaplain was accused of crimes including the theft of two pairs of stocks, four pairs of iron manacles, six iron chains with locks and five other chains.

This vignette suggests that all hospitals stood in need of reform and reveals how hospitals for the mentally disordered lagged behind the standards of care and enlightenment of all other hospitals. The biggest obstacle to humane treatment was still the unshakeable belief in mental defects being identical with moral defects, evidence of demon possession and ultimately signs of God's disfavour and righteous punishment. In a way, then, it mattered little to the parents or the idiots whether the attempt at exorcism and reinstatement or the offer of charity and protection was practised, for the end result was similar; misunderstanding, suspicion and a final washing of the hands by a society which had done its best and still failed.

Tillich (45) contends that the overarching philosophy of the Middle Ages was to deal with the situation in which one is put by a transcendent deity, so that each has and feels he has a place in the scheme of things. On these terms, could the fool or idiot be accepted, made room for and given freedom to offer his life in praise to God? Langland's reference to "lunatic lollers" (see

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(44) Courtney Dainton, 1961, The Story of England's Hospitals, 140

(45) Paul Tillich, 1967, Perspectives on 19th and 20th century Protestant Theology, 45-46

page 8) in fact describes what should be, not necessarily what was. The extent to which ordinary peasants and merchants practised the kindness so eloquently ordered, must remain unknown. In an article which has many exceptionable features, Goodenough (46) claims that the mentally handicapped were increasingly regarded as being indwelt by a good demon, were therefore especially close and dear to God, and their utterances took on the nature of oracles. They would have been included in the adage "only children and fools speak the truth", which finds Jewish corroboration in the disenchanted plaint "from the day of the destruction of the Temple the art of prophecy was taken away (from the professionals) and given to fools." (47). Against these hints of a "better way .. the way of love" we must set the contemptuous way of portraying fools in manuscripts, and the picture dating from 1215 which shows an obvious defective "cretinous, with three goitres, receding forehead and small head with the fool's staff grasped in the left hand and right hand supporting a toad." (48).

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(46) Erwin R Goodenough, 1951, The place of religion in the treatment of the mentally deficient, 120. To vindicate this writer's judgment, we cite two more sentences: "In dealing with the mentally deficient the value of religion cannot be ruled out because it speaks on a childish level ..." "In such a problem as the sterilisation of defectives, for example, ecclesiastical notions of the meaning of life and sex cannot be allowed to affect scientific judgment; if churches oppose what seem the best scientific procedure they must be resisted and circumvented."

(47) Baba Bathra 12a (Talmud); quoted in Kanner, op. cit., 6

(48) Professor Merke, 1960, The History of Endemic Goitre and Cretinism in the 13th to the 15th centuries, Proceedings of the Royal Society of Medicine; quoted in MacGillivray, op. cit., 4

The picture is taken from the "Musterbuch" of Reun, and Merke reckons it to be the oldest picture of a cretin. Such persons were viewed in the same light as the fabulous monsters of India and being quite incredible had nothing to do with medicine.

We do not think there is available evidence enough to answer the question posed in the previous paragraph; but a philosophical dispute undoubtedly raised the same issues. By reinstating the primacy of will over against the deification of reason in Aquinas, Duns Scotus was laying the foundations of existentialism, the contention that man's immediate experience reveals more completely the nature and traits of reality than man's cognitive experience. Because the "reason dominant" school won this battle hands down, and insofar as it was in the "will central" school that the best hopes lay for the mentally handicapped (i.e. by leaving room for irrationality, incalculability and nonconformity), we are compelled to the conclusion that by and large the fools and idiots were not accorded dignity and an equal but different place in God's world. And yet it might be nearer the truth to say that the church (and by extension, the state) did not practise what it preached. (49) What has surfaced by this point is the ambivalence felt by all in the presence of mental deficiency.

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(49) F.W. Maitland, 1898, Roman Canon Law in the Church of England, 100:-

"We could frame no acceptable definition of a State which would not comprehend the (medieval) Church. What has it not that a State should have? It has laws,law-givers, law-courts, lawyers. It uses physical force to compel men to obey the laws. It keeps prisons. In the 13th century, though with squeamish phrases, it pronounced sentence of death. It is no voluntary society; if people are not born into it they are baptized into it when they cannot help themselves. If they attempt to leave they are guilty of "crimen laesae maiestatis", and are likely to be burned. It is supported by involuntary contributions, by tithe and by tax. And, it may be added, it claims to over-ride, all the world over, the power of the secular State."

In the writer's opinion the debit entries in the above portrait of church-state relationships needs to be borne in mind alongside the popularly cited credit entries of tolerance,acceptance, the ability to sustain situations which could not be changed, the full dimensions that these ages allowed to the condition of "being human", etc. Indeed, a case could be made out for the church's kindness to the defectives (if that case is proven) merely reflecting the church's realisation that these were a captive audience, innocents, even a 'model' for responsible adults who should choose to reach that state of innocence the defectives were given by God.

By the nature of the case it is more difficult to produce documentary evidence of how the community cared for the mentally handicapped when they were seen as indistinguishable from the man in the street, than to lengthen the list of separate provisions made for them when seen as wicked and needing forgiveness or punishment, or weak and needing sustenance and protection. We know very little of what he did, only that St. Nicholas Thaumaturgos, the fourth century Bishop of Myra, ranks as the first man ever to make special provision for the mentally handicapped. He was their patron saint (but he 'belonged' also to all children, to sailors and to pawnbrokers)(50). Kanner does not spell out, either, what Eupraxia did in her Egyptian commune for the handicapped and the homeless (51). It is a safe assumption that defectives were cared for along with epileptics and lunatics at the famous 13th century hospital at Gheel, founded in tribute to the 'miracles' performed by St. Dympna. (52). They would almost certainly have been lodged along with the destitute in Hotel Dieu, founded in Paris in 829 (53). Increasingly in England the mentally ill and handicapped were housed in lazar houses as the disease leprosy, for which these were provided, was slowly eradicated (54).

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(50) Kanner, op. cit., 1

(51) ibid., 1

(52) E. Day, 1967, St. Dympna, N.C.E., IV, 1130

(53) Nasalli-Rocca, op. cit., 160

(54) Clay, op. cit., passim

The ambivalence hinted at can be briefly illustrated. In the first place the Catholic Church baptised all infants (those dying unbaptised were consigned to "limbo infantium" where they were cut off from the presence of God but not subject to His punishment), and in that sacramental action their original sin was removed "ex opere operato". Infused into the soul at baptism is "the habit of faith (a supernatural quality permanently inherent in the soul enabling us when we come to the use of reason to make supernatural acts of belief) and this is sufficient for salvation in the case of young children and all who do not come to the use of reason." (55). Defectives, then, even as adults would not be bound by the Fourth Lateran Council's requirement of Canon 31, viz. that each person should say his confession in privacy to the parish priest at least once a year and thereafter receive communion. We can safely classify the mentally handicapped with "all innocent unbelievers ("infideles negativi") whom God gives sufficient grace to achieve eternal salvation" (56) and arguably with those of "invincible ignorance and incapability" (57). In a paragraph purporting also to be a historical review, Noone speaks of modern Catholic practice wherein the mentally handicapped person should be prepared to receive the sacraments of penance and the holy eucharist "if he could understand the essential difference between right and wrong." (58)

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(55) Charles Hart, 1916, The Students' Catholic Doctrine, 12

(56) Ludwig Ott, 1966, Fundamentals of Catholic Dogma, 241

(57) ibid., 312 - in mind are those who were unevangelised

(58) J. J. Noone, 1967, Mental Retardation, N.C.E., IX, 664

From this evidence we conclude that the severely handicapped were treated as perpetual children (even to be envied because their state of sinlessness - through inability not accomplishment - carried them straight to heaven), and that mildly handicapped persons were prepared for the "adult's" sacrament, if they could distinguish right from wrong and discern Christ's presence in the bread. Two examples of the spirit of piety, of the doctrine of the nobility of suffering and the sharing in the Passion through innocent suffering, can be found in the sentiments of Flood. The idiot is responsible for occasioning thousands of acts of charity to himself and his parents, reminding countless of those who meet him to thank God for their healthy children and that they might have been thus burdened. Morons, the happiest and loveliest of children on earth, lack the use of reason and cannot sin, pleasing God as much as they unnerve some men. (59).

To summarise the state of affairs in pre-Reformation Christendom we must give more weight to the known theories and practices than to the ones for which evidence is scarce or entirely a reading back of contemporary attitudes. Parents, church and society seemed to swing between the poles of exorcism, leading to reinstatement or to excommunication, and of compassion embodied in hospital care of a punitive nature. There is a little evidence of popular toleration, mixed no doubt with at least verbal cruelty, and the continuing practice of giving fools a home and a role by the wealthier families. Lastly, there were some doctrinal compromises which sought to remove some of the blame and shame attaching to the mentally deficient.

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(59) Dom Peter Flood, 1971, God and Human Suffering, 12-13

C Post-Reformation Christianity

> For it may as rationally be concluded that the dead body of a man, wherein there is to be found no more appearance or action of life than there is in a statue, has yet nevertheless a living soul in it, because of its shape; as that there is a rational soul in a changeling, because he has the outside of a rational creature, when his actions carry far less marks of reason with them in the whole course of his life than what are to be found in many a beast. (60)

For our purposes we will narrow down the significance of the Reformation to a dispute about the method of interpreting the Bible and its message so interpreted. Catholics and Protestants alike held the Bible to be inerrant and to contain teaching which made it necessary for all men to be saved. As Tillich nicely puts it, for Catholics the church is the institution of salvation and in it is the spiritual community of the faithful, for Protestants the spiritual community of the faithful is the condition of the church as the institution of salvation (61).

At a stroke, the plight of the mentally handicapped worsened. The powerless and unreasoning, instead of having things done for them by the church, had to do things for themselves in order to join the church. Conditions for entry and the means of growth once within the church became more rationalistic in content and ethical in character. Thus the Scotch Confession of Faith, 1560, Art.XXIII:-

> We confesse and acknawledge that Baptisme apperteinis asweil to the infants of the faithfull, as unto them that be of age and discretion .. Bot the Supper of the Lord we confesse to apperteine to sik onely as be of the houshald of Faith, and can trie and examine themselves, asweil in their faith, as in their dewtie towards their Nichtbouris ... (62).

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(60) John Locke, 1690, An Essay concerning Human Understanding, Book IV, Ch. IV, Section 15

(61) Tillich, 1968, op. cit., 133

(62) Quoted in Philip Schaff and Henry B Smith, eds., 1877, Creeds of the Evangelical Protestant Churches, 474

Almost a century later, in 1647 the Westminster Confession of Faith and its accompanying Shorter Catechism underlined the new emphasis.

> Elect infants dying in infancy are regenerated and saved by Christ through the Spirit, who worketh when, and where and how he pleaseth. So also are all other elect persons who are incapable of being outwardly called by the ministry of the Word..(63)

> (intending communicants) must examine themselves of their knowledge to discern the Lord's body, of their faith to feed upon him, of their repentance, love and new obedience. (64)

Parents within, for example, the Baptist churches who had produced a mentally handicapped child were in even deeper trouble.

> Saving faith is an assent of the mind to the fundamental truths of revelation; an acceptance of the gospel, through the influence of the Holy Spirit; and a firm confidence and trust in Christ (65)

Not untypically, the Quakers managed to produce a statement which could be said to offer hope to the mentally deficient:-

> This certain doctrine then being received, to wit that there is an evangelical and saving light and grace in all ... Christ hath tasted death for every man, not only for all kinds of men, as some vainly talk, but for every one, of all kings ... even unto those who are necessarily excluded from the benefit of this knowledge by some inevitable accident. (66)

Predestination, the elect and only the elect responding to the preached gospel, their children alone worthy of baptism, the need for catechetical competence prior to confirmation and then infrequent communion and lifelong purity of life, represent a vastly different world from that of Catholic Christendom. In a regrettable way, it was a world even less forgiving of the mentally defective. Luther

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(63) Confession, Cap. X, ibid., 625. (As John Baillie, 1939, Our Knowledge of God, 71, observes, "this allows the possibility of a faith in which the element of assent is not conscious of itself... with regard to children and imbeciles")

(64) Catechism, Question 97, ibid., 697-698

(65) Confession of Free-will Baptists, 1834 and 1868, ibid., 753 This emanates from the nineteenth century but accurately describes their earlier viewpoint.

(66) The Confession of the Society of Friends, 1675, Sixth proposition; ibid., 793

met a sighted but evidently defective twelve year old boy and was asked for his advice. "Drown him" he replied. Wiser counsels prevailed, so Luther ordered prayers to be said "that the dear Lord take the Devil away." Within the year the boy died and Luther explained his joy at the news with these words:-

> Such changelings are merely a mass of flesh, "massa carnis", with no soul. For it is in the Devil's power that he corrupts people who have reasons and souls when he possesses them. The Devil sits in such changelings where their soul should have been. (67)

This outcropping of that fundamental ignorance, superstition and contempt deep in the racial unconsciousness; the allusion to changelings (popularly believed to have been substituted for the new-born infant prior to its baptism); and the pronouncement that such changelings have no souls and therefore offer nothing for God to work upon in saving grace, effectively place the deficient in the category of unevangelised heathen. And all depends on which theologian is consulted as to the fate they suffered.

As Nixon has demonstrated (68) Calvin both overestimated the uses of reason and underestimated its limits, but on a careful reading of Nixon's work we cannot find any references to those with no reason at all. Calvin's optimism shines through in remarks such as these:- "Reason tests the soundness of a doctrine, whether or not it is in harmony with the word of God" (69), "God has reserved the treasures of intelligence for his children; the rest of mankind is ignorant and stupid" (70).

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(67) Martin Luther, 1652, Colloquia Mensalia, ed. Wm. Dugard, 387; quoted in Kanner, op. cit., 7

(68) Leroy Nixon, 1960, John Calvin's Teaching on Human Reason, passim

(69) John Calvin, 1560, Institutes of the Christian Religion, Eng.tr., 1863 2nd.edn. Henry Beveridge (Edinburgh; Calvin Translation Society) I, 9 quoted in Nixon, op. cit., 124

(70) Institutes I, 73; quoted in Nixon, op. cit., 99

His pessimism is caught in the following sentences:- "Human discernment is so defective and lost that the first step in the school of Christ is to renounce it" (71) "Reason, though weak and immersed in darkness, was not totally destroyed by the fall; a shapeless ruin is all that remains." (72). MacGillivray writes without giving a source that "Calvin believed that the defectives were filled with Satan" (73).

Within the ranks of the defectives were the fools, still maintained in courts in Shakespeare's time:-

> I marvel what kin thou and thy daughters are:
> They'll have me whipped for speaking true,
> Thou'llt have me whipped for lying:
> and sometimes I am whipped for holding my peace

complains the fool in King Lear (Act 1 Scene 4). Psychotics, deaf mutes, physically deformed persons and epileptics were all grouped along with those we now term mentally deficient throughout the 15th to 17th centuries. At the close of the seventeenth century Aubrey wrote in his Natural History of Wiltshire 1659-1691:-

> Till the breaking out of the Civill Warres, Tom o' Bedlams did travell about the countrey. They had been poore distracted men that had been putt into Bedlam, where recovering to some sobernesse, they were licentiated to goe a-begging... they wore about their necks a great horn of an oxe in a string or bawdric, which, when they came to an house for almes, they did wind. (74)

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(71) ibid., I, 499; quoted in Nixon, op. cit., 115

(72) ibid., I, 233; quoted in Nixon, op.cit., 100

(73) MacGillivray, op. cit., 5

N.B. We would point out that as Calvin is in a direct line of descent from Aquinas, in terms of rational philosophy (as Luther is from Duns Scotus as an existential theologian) he would be disposed to disparage those with no reason as being far from God and an offence in an ordered world.

(74) Quoted in Jones, op. cit., 12

Bethlem, in common with every other hospital, had been changed due to Henry VIII's dissolution of the monasteries, and being made a municipal responsibility. Whether all the changes were for the better may be decided on our response to the seventeenth century physician who wrote:-

> Nothing is more necessary and more effective for the recovery of these people than forcing them to respect and fear intimidation. By this method the mind, held back by restraint, is induced to give up its arrogance and wild ideas and soon becomes meek and orderly. This is why maniacs often recover much sooner if they are treated with torture and treatment in hovels instead of with medicaments. (75)

In a concise review of eighteenth century theory and practice Jones outlines the common people's use of water rituals (when burning was forbidden) as a means of ousting the Devil from the demon possessed, e.g.:-

> At a well in Scotland the lunatic was stripped of his clothes, bound hand and foot, immersed in the sacred pool and then left all night in the chapel. If he managed to free himself of his bonds during the night there was a good hope of recovery.

Doctors were subject to varying standards of training and examination and many had not advanced beyond Hippocrates' humoural theory, using purging, vomiting and blood-letting as treatments. The Church of England had moved away from Death Judgment and Hell as sufficient means for ensuring obedience and reinforcing the status quo to a new philosophy in which a transcendent God created and judged in supreme uncaring isolation, so that Jenyns could write in his Free Inquiry into the Nature of Good and Evil in 1757:-

> The beauty and happiness of the whole depend on the just inferiority of the parts ... the sufferings of individuals are absolutely necessary to human happiness

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(75) Anonymous; quoted in Dainton, op. cit., 141

Philosophers were intoxicated with the heady wine that the highest good was to be well thought of and the virtuous man was he who won universal approbation (76).

Families began at this stage to "put away" members of their families who brought them shame, usually in some deserted place where their existence might be forgotten and the family scandal allowed to die down. Others were kept at home to receive medical attention, but far more were tied or chained in a corner of the house or in a cupboard under the stairs to prevent them from becoming a nuisance to other people. These practices applied indiscriminately to idiots and lunatics. It is true that one or two early attempts at differential diagnoses had been made. A statute dating from 1325, De praerogativa regis, Edward II decreed:-

> to protect the lands of idiots (i.e. natural fools) and take the profits of them and provide for their necessities and to render the lands on their death to their right heirs; and
>
> to provide for the safe keeping of the lands of lunatics (i.e. persons of unsound mind) so that the lands might be restored to them on their recovery or to their representatives on their death (77).

Fitzherbert in 1534 thought that failure to count to twenty pence, tell his age and identify his mother and father made the subject clearly an idiot; and Swinburne in 1591 reckoned that failure to measure a yard of cloth and name the days of the week was sufficient proof of idiocy. In view of his dismissive estimation of changelings (see page 24) Locke surprises us by distinguishing between lunatics and defectives. "Madmen put wrong ideas together and so

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(76) Jones, op. cit., 2-7

(77) Quoted in L.T. Hilliard and B.H. Kirman, 1957, Mental Deficiency, 1

make wrong propositions, but argue and reason right from them, but idiots make very few or no propositions and reason scarce at all"(78). Little popular or medical attention was paid to these early insights.

Another effect of the Reformation, besides its theological disadvantagement with regard to the defective, was that the new doctrine of work pushed the defective even further into oblivion. Whilst no one could presume to know that he was one of the elect, a careful reading of the New Testament would reveal the virtues manifested by the elect, namely industry, honesty and frugality. In the writings of Weber (79) one can find a classic statement of the interplay between religious and sociological factors; all we note is that the effect on the mentally handicapped was catastrophic. They were neither able to meet the theological demand of believing in a propositional Christianity nor the ethical demand of fulfilling their calling in work. Few stopped to distinguish between those who were unable and those who were unwilling to conform. Thus it came about that mentally defective subjects were lumped together with the indolent, paupers and criminals. Many, in consequence, were committed to Bridewells (in which beggars and vagrants were housed at public expense), to gaols (where convicted criminals paid their own way as well as the staff) or to workhouses and poorhouses (where paupers existed on municipal funds pared to the bone). Some may even have suffered the fate of being committed to private madhouses run by charlatans such as this one:-

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(78) Locke, op. cit., Book II, Chap. XI, Section 13

(79) Max Weber, 1920, The Protestant Ethic and the Spirit of Capitalism, passim (Eng. tr. T. Parsons)

> In Clerkenwell Close, where the figures of Mad People are over the Gate, liveth one who by the blessing of God cures all Lunatick, distracted or mad people; he seldom exceeds three months in the cure of the Maddest Person that comes in his house; several have been cured in a fortnight and some in less time: he has cured several from Bedlam and other madhouses in and about the city, and has conveniency for people of what quality so ever. No cure - no money. (80)

Those mental defectives who were sent into the new municipally run hospitals were scarcely any better off. Tenon protested at the conditions of the Hotel Dieu in Paris 900 years after its opening, where all but the smallpox, obstetric, accident and surgical cases were indiscriminately mixed, convalescent and dying, mentally and physically ill, sleeping 4-6 to a bed only 4' 4" wide in unheated, unventilated and insanitary wards; conditions which were no different in Bicetre or Salpetriere in Paris. (81). In York, Tuke was so distressed by conditions in the Asylum (founded 1777) that he founded as an alternative the Retreat in 1792, run on Christian principles and common sense. (82).

The other possibility open to the parents of defective children was to have the adolescent accepted in a noble household as the fool.

> "In 'Waverley' published in 1814, we have an excellent description of the able-bodied mental defective in the character of David Do Little or Davie dae nothing. In Scotland the custom persisted till late in the 18th century of keeping a household fool. At Glamis Castle is preserved the dress of one of these jesters, very handsome and ornamented with many bells. (83)

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(80) Quoted in Dainton, op. cit., 142

(81) A.B. McPadden, 1967, History of Hospitals: 1500 - Present, N.C.E., VII, 163-166

(82) ibid., 164

(83) MacGillivray, op. cit., 6

In summarising the developments, perhaps the changes, in the care of the mentally handicapped we reiterate the double burden imposed on them by virtue of Protestant theology and political theory. Firstly they were unlikely to pass muster as church members in the full sense because of their lack of reasoning power and understanding of what they might at a pinch learn by rote. In the second place they could not fulfil their calling in work, with a very few exceptions such as the household fools. They suffered from the stringencies imposed by the Elizabethan Poor Law of 1601 which tried to reduce dependency by making it as distasteful as possible by encouraging employment as a more desirable alternative. They embarassed their families and ended up either locked in dark places at home or in hospitals, Bridewells, gaols, work/poor houses or private madhouses. In gaols they were separated from criminals in order to ensure preferential treatment for the prisoners (84). They served as sport for idle visitants, the Sunday afternoon 'penny' onlookers and suffered from neglect or totally inappropriate hardship of regime.

Throughout the entire period under review in this chapter we have encountered strong emotional forces often in conflict with each other, fear versus pity, blame versus honour, rejection versus protection; we have distinguished two constructs of the condition, that which defined mental deficiency as a problem of the will and that which epitomised it as a problem of the reason; we have noted the gap between what was said and what was done, church and society on occasions acting more kindly, on occasions more cruelly, than they pronounced; we have discovered that the intention behind and

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(84) 1763 Act led to the segregation of "persons of insane mind and outrageous behaviour" from "going in common with other prisoners" but with a view to promoting the prisoners' welfare; quoted in Jones, op. cit., 23

the result of certain human interventions were sometimes contradictory. Such a history is not a unilinear progression so much as a network of ideas, values and means; social consciousness has not always wisely informed social conscience.

We have two further considerations to proffer. Severely handicapped children might well have died in or around the birth process or in early infancy, thus reducing their overall numbers. Mildly handicapped children might well not have been detected as in any remarkable way different from their siblings, and as adults would blend completely into the social background of a rural or small town population. From these hypotheses, then, we might explain the relative paucity of data which relates exclusively to the mentally deficient, and would suggest similarly that their small numbers could be said to exonerate society from according to the defectives much dignity or any potential worth realising.

Chapter 2 Developments in the study and care of the mentally handicapped from the nineteenth century to the present

> Mental handicap does not yield to dramatic cures, is usually depressing to contemplate and, unlike mental illness, is never the subject of fascinating psychological or literary speculation. Consequently the level of public interest in mental handicap appears in general to be relatively low. (1)

It was as ironic to open the first chapter on public attitudes and treatments with a quotation admitting professional bewilderment, as it is to start the second chapter on professional definitions and provisions with a quotation indicating public indifference. However, it has been the fate of the mentally handicapped, by and large, to be successively ignored by the professions and tolerated or treated by the public; and studied and served by the professions and ignored by the public. We account for the paradoxical state of affairs at present by means of a concise statement of the four phases of professional intervention in the field of mental handicap in the period under review.

In the first instance the teachers sought to apply a cure for mental handicap without understanding its cause. Secondly, the doctors clarified ever more clearly the causes and varieties of the condition without offering a cure. Thirdly, the administrators enacted a policy of control through containment after first universally condemning the feeble-minded as dangerous to national intelligence and public morals. Finally, the sociologists and social workers are pleading for a total reversal of that policy. In its place they advocate phasing out institutional facilities and expanding community services for the mentally handicapped, who are seen as like us but slower rather than unlike us and menacing.

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(1) M. Bone, B. Spain and F.M. Martin, 1972, Plans and Provisions for the Mentally Handicapped, 1

Their absorption within the mainstream of society would be mutually beneficial; the mentally handicapped enjoying better life-chances, society adopting a less sophisticated life-style.

Notwithstanding this ambivalence on the part of the experts involved at first hand with them, the beginning of the nineteenth century marked the dawn of a new day for the mentally handicapped. The positive influences of the French Revolution's call to "Liberte, Egalite et Fraternite" and Victorian philanthropism, which embraced most of that age's weak and broken individuals, gave the mentally handicapped a new dignity and recognised in them a potential worth realising. The advances made in the first seventy years or so of the nineteenth century were lost in the period of the eugenics scare with its practices of sterilisation or colonisation throughout the reproductive life of the defectives, and the abandonment of educational means and ends. Once again the tide is turning in favour of the mentally handicapped. There is an inter-professional approach in the delivery of services to the handicapped and their families, and a campaign to promote the rights of the handicapped and re-educate the attitudes of the public. This chapter will describe in more detail the four phases of study and care outlined above and devote a section to the definition and prevalence of mental handicap.

A Educational and Medical Pioneers

> It is in truth a noble and exalted idea that, through human exertions, a mind may be awakened in what was apparently a senseless mass, and that even education may be extended to those who have been hitherto considered beyond the reach of instruction and incapable of intercourse with their fellow creatures. (2)

In 1803 Abbe Bonaterre brought to the Institution for Deaf Mutes in Paris a naked, mute, wild, incontinent eleven or twelve year old boy, world famous as Victor, the Wild Boy of Aveyron. Itard, a doctor-cum-educationalist, influenced by Pestalozzi's educational theories and inspired by Pereire's success with deaf mutes, vowed to bring him "from savagery to civilisation, from natural life to social life." He would achieve this end by means of training his senses, widening his experiences and expectations, and increasing his imitative and inquisitive skills (3). Five years tuition showed small but real improvements in his skills and the French Academy of Science praised Itard for his patience, intelligence, sagacity and courage. Itard was disappointed, however, and for the last twenty years of his life Victor was maintained in custodial care without the benefit of further educational stimulation.

In 1836 Guggenbühl, a Swiss doctor, came across a dwarfed, crippled cretin of stupid appearance mumbling the Lord's Prayer before a wayside cross in Seedorf. So moved was he by this spectacle that Guggenbühl pledged his life thereafter to the cure and prophylaxis of cretinism. Encouraged in this resolve by Fellenberg, an

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(2) William Twining, 1843, quoted in Kanner, op. cit., 26

(3) ibid., 12. The bulk of the historical review is dependent on Kanner's work.

innovator in teacher-training, Guggenbühl gave up his medical practice saying, "God has chosen another course for me and I must heed his call." He established at Abendberg in 1840 a school for cretins where they enjoyed mountain air, a protein diet, bodily exercises, various medical treatments and sensory stimulation. The staff were drawn from the Evangelical Sisters of Mercy. This centre was much visited, highly praised and widely copied. There were critics, however, distressed by the founder's megalomania and suspicious of his alleged 'cures'. An official tour of inspection by them revealed bad hygiene, poor inmate control and low staff morale. Abendberg was closed down around 1858 and Guggenbühl died five years later a discredited man.

Seguin, another French doctor-cum-educationalist, worked for a while with Itard and then with Pinel in the much reformed Bicetre Hospital in Paris. In 1846 he published his text book on the education of idiots, receiving a letter of commendation from Pope Pius XI. Two years later he sailed to America where he became the founding father of the characteristically education-oriented approach to mental handicap in that continent. One of his early disciples was Howe, a man inclined more to nativism than to Seguin's sensationism. Nativists argued that intelligence was hereditary, and where it was lacking the most one could hope for was meaningful occupation rather than academic learning. Sensationists, on the other hand, claimed that even in the case of idiots and imbeciles progress towards literacy and normality was possible if the sensory stimulation was varied.

The newly respected, and respectable, mentally handicapped captured the interest and effort of many Christian philanthropists as well as teachers. The following list from Kanner indicates the extent

of ecclesiastical involvement:- in France, Bost (musician, horse lover and soldier turned theologian) opened five residential schools before his death in 1881; in Germany, Löhe (a pastor) rented rooms for mentally deficient children, Sengelmann (a pastor) started a school and asylum for defectives and published an early standard text book called "Idiotophilus", Probst (a priest) founded a residential school, Barthold directed a school jointly sponsored by church, government and civic organisations, and von der Recke Volmerstein opened a Samaritan asylum for incurable, sick, paralysed, crippled, blind and feeble-minded children (Kanner: "probably the only institution in history which, without any pretence at specialisation, aimed at extending help to children with all and every kind of malady or anomaly" p. 54); in the Netherlands, von Koetsvelt (the court preacher) was instrumental in opening a day school for thirty educable mental defectives in 1857; in Switzerland, Appenzeller (a pastor) with the help of a charitable society began an institution for thirty children; in Denmark, Duurloo (a pastor) directed a farm-colony, and Keller (a theologian) established three schools for deaf mutes, one for teachable mental defectives and one for idiots; in Sweden, Glassell (an army chaplain) founded the first school for defective children; in Austria, the Congregation of the Sisters of the Holy Cross were pioneers; in Belgium, the Brothers of Charity opened a school three years before the Sisters of Charity followed suit.

"In most instances," Kanner writes, "religious sentiments rather than medical curiosity or zeal were the guiding principles." (4). That there was some self-interest in this burgeoning of

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(4) ibid., 55

ecclesiastical endeavour is indicated in the chapter Kanner devotes to early periodicals. He states without evaluative comment:-

> Much time was taken up by theological issues. Pastoral influences on the patients were declared to be more important than either medical or pedagogical services. Prayers for and by the inmates were declared to be the principal methods, and "strengthening of the Christian character" the principal aim. A big debate arose about whether feeble-minded youngsters should be confirmed. It was urged that a ruling of the Evangelical Consistory of the Kingdom of Saxony be generally adopted, viz. "Feeble-minded children who have at least some knowledge of the three articles of the Christian faith may not be excluded from confirmation. (5)

Thus at least part of the church's motivation was to increase its own membership from the ranks of newly literate defectives who had hitherto been excluded from eligibility for church membership because they could not make the grade as catechumens.

As a result of Twining's propaganda on his return from Abendberg, the first school for idiot children in Britain was opened in Bath in 1856, in part of Magdalen Hospital, formerly a leprosarium. The fact that the school was in a hospital, rather than that education was being offered to idiots, would seem to have determined the medical "character" of mental handicap in this country. The following year, Reed, a nonconformist minister and philanthropist; Connolly, superintendent of Hanwell Psychiatric Asylum (the first to offer the mentally ill education) and Gaskell, the publisher in Britain of Seguin's works, shared a platform "pleading the cause of those who cannot plead for themselves." Resulting from this, the first metropolitan provision for mental defectives, Park House, Highgate was opened in 1848, and a Sister of Charity was recruited to help in its running. Guggenbühl visited this establishment and petitioned Lord Ashley, M.P. to make the education of the feeble-

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(5) ibid., 76

minded a matter of governmental concern and priority.

In Scotland, Sir John and Lady Ogilvy, in gratitude for the care shown to their son in Abendberg, opened an institute at Baldovan near Dundee (now Strathmartine Hospital) in 1854. One year later Larbert Hospital near Falkirk opened its doors, as did a school in Gayfield Square, Edinburgh, its objects for the defective children being:-

> Firstly, improvement in general health; secondly, the awakening and development of mental powers by those means which have already been found so effective in similar institutions. Thirdly, the employment of educational resources to meet the peculiarities of the pupils. Fourthly, in the case of the more advanced pupils, of providing some suitable occupation giving healthy employment at once agreeable and profitable to all their powers, keeping in view such occupations as may fit the pupil for future usefulness and intercourse with society.(6)

Columbia Lodge at Liberton, near Edinburgh, a Training School for Imbecile Children was opened in 1867; "the children belong to the wealthier classes and their comfort is well attended to" (7), "but, as a rule, their mental deficiencies are too great to allow of any great expectation of favourable results from training." (8)

In Ireland, eight years after a census had revealed 7,033 defectives, the Stewart Institute was opened at Palmerstown on the outskirts of Dublin in 1869. Eire, predictably, has had a long and rich association between special orders within the Catholic Church and the care of defectives.

Medical pioneers were not only interested in diagnosis but also in the educational potentialities of their hospital's inmates. Down

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(6) Quoted in MacGillivray, op. cit., 10 - 11

(7) Report of General Board of Commissioners in Lunacy for Scotland 1869, 11th Report, lxv

(8) ibid., 1870, 12th Report, lxxiv

identified Mongolism in 1866, writing:-

> A very large number of congenital idiots are typical Mongols. So marked is this that when placed side by side, it is difficult to believe that the specimens compared are not children of the same parents ..... these examples of the result of degeneracy among mankind appear to me to furnish some arguments in favour of the unity of the human species.(9)

Shuttleworth called them "unfinished children" in 1866; Wm.Ireland denied that there were any in the East of Scotland! Down distinguished between congenital, developmental and accidental types of mental handicap. Ireland, for ten years superintendent at Larbert, made twelve subdivisions (genetous, microcephalic, eclampsic, epileptic, hydrocephalic, paralytic, traumatic, inflammatory, sclerotic, syphilitic, cretinism and idiocy by deprivation) in his "On Idiocy and Imbecility" in 1877. He proposed a five-fold educational target depending on whether they were able to speak or understand speech; understand a few words; speak and be taught to work; be taught to read and write, and be taught to read books for themselves (10).

Meanwhile in Germany the distinction between cretins and idiots, hinted at by Fodere, was made complete by Griesinger, who wrote in 1876, "Every cretin is an idiot, but every idiot is not a cretin.(11) Two options were open to the medical-cum-educational experts in the middle of the nineteenth century. They could address themselves to the educability and social behaviour potentialities of defectives,

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(9) John Langdown Haydon Down, 1866, Observations on an Ethnic Classification of Idiots, London Hospital Reports 1866, 3. 25 J. Ment. Science, 13. 121-123, 1867; quoted in Kanner, ibid., 97-99

(10) Quoted in Hilliard and Kirman, op. cit., 2

(11) Quoted in Kanner, op. cit., 88
Some villagers saw cretins as "targets of God's wrath, which spared the rest of the populace; take them away and the ire of the Lord might look for other victims" ibid., 93

or they could study and describe the nature of the many manifestations of mental deficiency. In the event, the parting of the ways was crucial. It cannot only be intended of marriage that those whom/which God has joined together let not man put asunder.

B Feeble-mindedness and Custodial Asylums

> Feeble-mindedness is hereditary and transmitted as surely as any other character .... therefore, segregation through colonisation seems in the present state of our knowledge an ideal and perfectly satisfactory method of care. (12)

Through a series of circumstances at the close of the nineteenth century, feeble-mindedness assumed sinister significance. In the fever of Victorian industrialism an efficient labour force was of paramount importance. The lot of the indolent and incompetent (not always distinguished) was grim, for they were exposed to the stigma and deprivation of life in workhouses or gaols run by high minded officials with penny pinching attitudes. As in earlier ages, their failure to work was held against the mentally handicapped, and a swingeing attack was made on them for other shortcomings by Galton. He first expressed his concern for the intellectual destiny of the human race (or that near synonym, the British Empire!) in 1865, which was threatened by the unchecked breeding of the unfit. By 1883 he had coined the term "eugenics" to refer to "all the influences that improve the inborn qualities of a race". The defectives, on the contrary, worsened and weakened the stock, and were both promiscuous and fertile.

Popular scientific studies in America include Dugdale's life story of the Jukes (13), followed up by Estabrook who concluded forty years later that not all feeble-minded Jukes were criminals; but that all Juke criminals were feeble-minded; and half the Jukes were, and are, feeble-minded (14). Most famous is Goddard's study

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(12) H.H. Goddard, 1912, The Kallikak Family: A study in the heredity of feeble-mindedness; quoted in Kanner, ibid., 132

(13) W. Dugdale, 1877, The Jukes: A study in crime, pauperism, and disease and heredity

(14) A.H. Estabrook, 1916, The Jukes in 1915

of the Kallikak family; Martin of that ilk fathered by an indiscreet liaison with a simple-minded woman a veritable "Who's Who?" of social miscreants, misfits and malingerers, and by a legitimate union later on a long line of honest, thrifty and virtuous citizens. In 1891 a clergyman named McCulloch called for the cessation of out-door relief, private benevolence and other measures, and for the rounding up of the children of defective parents, who were 'akin to the tribe of Ishmael, a decaying stock and festering mass'. Davenport wrote unequivocally in 1911, "Two mentally defective parents will produce only mentally defective offspring." (15)

The most forthright description of defectives to emerge from this period is by Fernald, who wrote in 1912:-

> The feeble-minded are a parasitic, predatory class, never capable of self-support or of managing their own affairs. The great majority become public charges in some form. They cause unutterable sorrow at home and a menace and danger to the community. Feeble-minded women are almost universally immoral and if at large become carriers of venereal disease or give birth to children who are as defective as themselves. Every feeble-minded person, especially the high grade imbecile, is a potential criminal, needing only the proper environment and opportunity for the development and expression of his criminal tendencies. (16)

In the light of this, not surprisingly sterilisation laws were enacted (in which defectives were lumped together with psychotics, psychopaths and criminals) in many countries, among them America, Canada, Denmark, Finland and Switzerland. Defectives were segregated for life, or at least their adulthood, in long-term,

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(15) Charles B. Davenport, 1911, Heredity in Relation to Eugenics, 166; quoted in Kanner, ibid., 131

(16) Walter E. Fernald, 1912; quoted in Morris, op. cit., 10

isolated and vast asylums or farm colonies. As Kuhlmann wrote:-

> Abandonment of the idea of cure was the important factor in the development of the physical plant ... the view that all mental defectives should be committed to state institutions for life grew rapidly after the momentum it had gained by 1900. In another ten years it had become unanimous as opinion ever had been on anything concerning mental defectives. (17)

Events took a slightly different turn in Britain. A Departmental Committee on Prisons reported in 1895 that the feeble-minded "spend their lives in circulating between the prison, the asylum and the workhouse." (18) Regretting this dismal state of affairs, the Report recommended rather that defectives should be confined in asylums where there is no risk of injury to themselves or to others, or in farm colonies where, prevented from crime and procreation, they will be saved "the needlessly rigorous treatment to which they are at present subjected."

Reinforcing the recommendation of that Report, Tredgold wrote in 1909 in the inaugural edition of The Eugenics Review:-

> I would lay it down as a general principle that as soon as a nation reaches that stage of civilisation in which medical knowledge and humanitarian sentiment operate to prolong the existence of the unfit, then it becomes imperative on that nation to devise such social laws as will ensure that those unfit do not propagate their kind. (19)

He and his colleagues, however, were unsuccessful in persuading Parliament to enact sterilisation laws. A typically British compromise was reached under the terms of the 1913 Mental Deficiency Act which allowed the segregation of ascertained defectives in asylums throughout the length of their reproductive

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(17) F. Kuhlmann, 1940, One hundred years of special care and training, Amer. J. Ment. Deficiency, 45. 8-24; quoted in Kanner, ibid., 84

(18) Departmental Committee Report on Prisons, 1895, 34; quoted in C. J. Guthrie, 1920, Prisons, E.R.E., X, 345-346

(19) A.F. Tredgold, 1909, Eugenics Review, 1. 100; quoted in Hilliard and Kirman, op. cit., 5

lives; a de facto if not de jure sterilisation. Many women, indeed, were admitted to such asylums precisely because they had borne illegitimate children.

Fernald did an about face as a result of his experiences, writing in 1924 that he recalled the horror and aversion with which the defectives were viewed and shunned, whereas the danger comes from the "neglected, untrained and uncared for defectives." (20) Notwithstanding this confession of misguided zeal in his earlier days Fernald and his colleagues in most countries furthered a policy which can only be described as one of sanitisation, i.e. collecting all society's rubbish together in one place and keeping it under control and out of sight.

Feeble-minded children had their fate decided by events in France whose repercussions spread around the world. Whilst education for all was only compulsory from the 1870's, already it had become apparent that some children were not going to keep up with their peers. Just how many would be slow learners became apparent when Binet published the results of his researches in Paris in 1905. Employed a year earlier to help weed out of the public schools those children who would be unlikely to cope and so hold back their classmates and teachers, Binet asked thousands of children of different ages to perform tasks of varying complexity. The analysis of these test scores produced the equation, mental age divided by chronological age equals Intelligence Quotient. Henceforth, idiots were measurable with an I.Q. less than 25, imbeciles

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(20) W.E. Fernald, 1924, Thirty years progress in the care of the feeble-minded; Proceedings of Assn. Med. Offs. Amer. Instns. for Idiotic and Feeble-minded Persons, 29. 206-219; quoted in Kanner, op. cit., 135

fell between I.Q. 25 and 50, and the feeble-minded had scores ranging from I.Q. 50 - 70. The educational needs of the feeble-minded quickly became a priority (in the interests, that is, of the able who should not be held back by intermixing with the less able). It is true that the first special class antedated Binet by almost forty years, Dresden establishing one in 1867. Other countries followed Germany's lead, but supposed that a few special classes would suffice. Binet's work, adopted as a yardstick in every developed country, revealed the wholly undreamed of proportions of the feeble-minded population.

In Scotland two special schools were established in Glasgow in 1898; legislation empowering separate provisions on a day basis for epileptics and defectives reached the statute book in 1906, but the first school implementing that Act's requirements was not built in Glasgow until 1914, and its first child guidance clinic did not appear until 1937 (21). The 1913 Mental Deficiency Act defined mental handicap as "arrested or incomplete development of mind existing from birth" (amended to read "..... existing before the age of 18 years whether resulting from inherent causes or induced by disease or injury" in the 1927 Act). The coincidence of Binet's I.Q. scales and this legislation resulted in three levels of classification. Idiots were ineducable and untrainable and provided for in day nurseries; imbeciles were ineducable but trainable and provided for in occupation centres where minimal literary and maximum occupational skills were taught; feeble-minded children were educable but at a slower pace and to a lower ceiling than normal children. With little change this device of the diagnosis determining educational prospects and methodology

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(21) MacGillivray, op. cit., 11

remained the case until the early 1970's.

The 1913 act, referred to earlier, authorised District Boards of Control to provide institutions for the mentally handicapped separate from asylums which thereafter should concentrate on the mentally ill. In 1924 Edinburgh District Board of Control bought Gogarburn mansion house and estate, previously used as a home for convalescent and delicate pre-school age children. Originally there were 24 female patients, then 15 males occupied the converted stable block, and the farm was bought "to protect the privacy of Gogarburn and provide useful work and food for the patients." (22) In 1929 the Duke of York, later to become George VI, laid the foundation after a speech which declared:-

> Gogarburn Hospital is a means of ministering not only to the needs of the capital city but of a large area of south east Scotland ... a sign of the earnestness with which the people of Scotland are endeavouring to solve the problem of providing for the mentally handicapped.

The architect designed the colony "as a small village with houses or blocks each to accommodate 50 patients under the supervision of a housekeeper or sister, so that a more homely atmosphere can be attained than is possible in a barrack block" (sic). In 1931 a special school opened in the grounds for 20 pupils, the teacher supplied by the Corporation. Midway through his 35 years tenure of office the first superintendent, Bailey, mentioned a perhaps untypical amount of local involvement when he wrote:-

> Our views are probably regarded as unorthodox but we consider occupational therapy as recreational - interest should be the mainspring, not direction; and that is why we have no professional occupational therapist but rely on the enthusiasm of twenty voluntary ladies.

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(22) The historical data on Gogarburn comes from an unpublished article, due for inclusion in a brochure, by F. Catford, to whom this writer is grateful for permission to quote these extracts

By way of summary, we may recall the following swings and shifts in professional and public expectations and provisions from the early nineteenth century to the last decade. Idiots and imbeciles were exonerated in the beginning, then blamed for failing to respond to educational and medical 'cures' which were offered with devotion and diligence; such failure on their part must be a sign of ingratitude. Feeble-minded adults, throughout blamed for their indolence, were additionally accused of plunging society into intellectual bankruptcy and moral degeneracy, and were collected together with the once more blameworthy idiots and imbeciles in asylums whose size and remoteness militated against public interest and involvement. These asylums increasingly moved away from short-term cure to long-term care aims, replacing educational by occupational, remedial by custodial methods. At the outset, educational excellence was expected of the severely handicapped; at the close, minimal competence was expected of the mildly handicapped. Something of society's sadness is reflected in the fact that the change-oriented procedures proving less than successful, the acceptance-oriented procedures were less than excellent.

C Community Responsibilities and Resources

> Society should be secure enough to take from earlier social traditions and earlier social structures that vital element of group and community support which is what we have lost and must now rediscover ... It is essential, therefore, for the social system to be a learning and supportive system which does not weaken, but actually reinforces, the self-image and autonomy of each individual human being; and it is of crucial importance that this should happen most decisively - and be seen so to happen - precisely where whole groups of human beings have been labelled as mentally handicapped and relegated to an inferior status. (23)

The last decade has seen a revolution in attitudes, at least amongst the professionals in the field and arguably within the general public. Measured criticisms were made against not only the size and ethos of asylums, but even of their "raison d'etre", in articles by McKeown (24) and others, in Townsend's foreword and Morris's book (25), in books by Tizard and others (26), and in reports on two hospital scandals (27). In effect these all told the same story. The hospitals are too large, too isolated, run on

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(23) T. Drummond Hunter, 1973, Changing Patterns in Organisation and Management, IN A.D. Forrest, B. Ritson, A.D. Zealley (eds) New Perspectives in Mental Handicap

(24) T. McKeown, 1967, Brit. J. Prev. Soc. Med., 21. 3, July
1967, Brit. Med. J., 3. 567, September
1970, Brit. J. Prev. Soc. Med., 24. 2, May

(25) P. Townsend, 1969, Foreword: Social Planning for the Mentally Handicapped, xi - xxxiii. (See also, Limiting Factors in Policy Making, 1972 IN Action for the Retarded)

P. Morris, 1969, Put Away: A sociological study of institutions for the mentally retarded

(26) N. O'Connor and J. Tizard, 1956, The social problems of mental deficiency: J. Tizard and J. C. Grad, 1961, The mentally handicapped and their families: J. Tizard, 1964, Community services for the mentally handicapped

(27) H.M.S.O., 1969, Report of Committee of Inquiry into ..... Ely Hospital, Cardiff (3975)
H.M.S.O., 1971, Report of Farleigh Hospital Committee of Inquiry (4557)

too small a budget, require so little medical care for most patients that staff suffer "goal displacement", low morale and even indulge in occasional cruelty, and so on. They argue, in the main, that mental handicap is rather a community phenomenon than a hospital problem, and community resources need to supplement if not replace the hospitals. Defendants of the hospitals include Elliott (28) who described the reforms he carried out in Birmingham's mental subnormality hospitals; Gunzburg (29) who claimed that notwithstanding the in-built drawbacks, hospitals could still care for the mentally handicapped and effect socialisation/normalisation programmes; Hunter (30) who wanted the (retained) hospital to be seen as "the-hospital-in-the-community" intimately related in a network of facilities with general medical, educational and social work agencies; and Forrest, Ritson and Zealley (31) who, whilst admitting the validity of many of the criticisms of the hospitals, still claim a place for them as centres of excellence for a wide range of persons including the severely subnormal, the physically handicapped, those needing continuous nursing care, the brain damaged, the emotionally disturbed, the psychotic and the behaviour disordered. There is still ambivalence at the highest levels "with successive governments pursuing simultaneously two policies, on the one hand diminishing and on the other hand increasing the

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(28) James Elliott, 1970, A better deal for the mentally handicapped; First steps in the East Birmingham group

(29) H.C. Gunzburg, 1970, The role of the hospital in the social education of the mentally subnormal adult

(30) Hunter, op. cit.

(31) Forrest, Ritson and Zealley, Mental Handicap, IN Forrest A D (Ed), Companion to Psychiatric Studies, II, 458-487, 1973

already large role played by hospitals in the total system of services for the handicapped" as Townsend wryly observes (32). Nevertheless, mental deficiency nursing has been given a new status and a clearer understanding of its own role vis-a-vis many other professionals in the Briggs Report (33).

On the educational front a significant blow was struck by legislation enacted in 1971 in Scotland, as a result of which no child is now unsuitable for education at school, and all schools are now the responsibility of Local Authority Education Departments; the extent of this Act's implications for standards of staff-training in all centres where the mentally handicapped are supervised/trained/taught are spelt out in the Melville Report (34). Social Work Departments are gradually taking more seriously their authorisation to provide more community-based services for the mentally handicapped such as play groups, nursery schools, day centres, residential hostels, junior occupation and senior training centres, etc.

Within the year, 1973, in which this is being written three significant new developments have occurred in Britain. An Association of Professions for the Mentally Handicapped has been formed which aims to represent the interests of the mentally handicapped generally, and when legislation is pending, and to increase multi-disciplinary contacts, parity of esteem and cross-

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(32) Townsend, 1972, op. cit., 55

(33) H.M.S.O. 1972, Report of the (Briggs) Committee on Nursing (5115)

(34) H.M.S.O., 1973, (Melville Report on) Training of Staff for Centres for the Mentally Handicapped

fertilisation of ideas between the various professions. The British Association for the Retarded has come into being, strongly representative of the National Society for Mentally Handicapped Children, and sees itself as a pressure-group. Manchester University has appointed a Professor in Education of the Mentally Handicapped. Excepting the Moscow Institute of Defectology, this is the only such post in Europe.

How are we to account for this renewal of interest and concern? In the first place the significance of the Kennedy family in America cannot be over-estimated. The late President used the fact of his sister's profound mental retardation as a lever for releasing Federal funds and evoking public sympathy. Much as George III's episodic madness did for mental illness, this potential tragedy in America's "First Family" issued in a general improvement in the lot of the mentally handicapped across national, racial and social class boundaries. Secondly, the permissive age has seen together with a relaxation of personal morality - as the church defined it - an upsurge of social conscience for all weak or handicapped subjects. Thirdly, the sense of personal liberation hinted at above has led to the doctrine of "doing your own thing". Many youngsters, at least, can accept and enjoy the company of the mentally handicapped without being griefstricken at their fate or disconcerted by their oddity and unpredictability. Fourthly, a new spirit of co-operation has characterised the experts in the field insofar as, confronted by the limits of their own ability, they see the benefit for all concerned in a joint approach to the study and care of the mentally handicapped. Fifthly, and as an obvious extension of this trend, the growing strength of parents'

organisations and voluntary societies has led to a clarification and better implementation of the distinctive roles each person or group can play. In the sixth place, the implications of the 'normalisation' movement in Scandinavia have penetrated into most developed countries; the mentally handicapped deserve justice not charity, and should be given as many 'normal' life-chances as possible whilst living 'undifferentiated' in the community. Finally, the church (once vocal and active in the educational optimism era, and vocal as guardian of public morals in the eugenics scare) has begun to exercise itself on behalf of the mentally handicapped. In Scotland, for example, the Church of Scotland runs a short-stay holiday home for mentally handicapped children in Stonehaven, and in Edinburgh has created a pioneer post for an assistant-minister-cum-hospital-chaplain, designed to increase understanding and involvement between Gogarburn Hospital and the wealthy suburb on the edge of which it stands.

D Definition and Prevalence of Mental Handicap

> Because of the better chances of survival the pathological numbers are increasing; consequent upon the complexity of the culture patterns in many developed countries, the cultural numbers may be emerging at an even greater rate.(35)

In view of Kanner's confusion (see page 1) a layman essaying a definition of mental handicap is greatly disadvantaged. However, knowing 'that it is' is rarely enough for man who wants to know 'what it is' and how it can be changed or harnessed. In the Hebraic myth of Genesis 2:18 - 20 all living creatures were brought to Adam and whatever he named them, that was the name thereof. In the modern myth any problem once it is defined accurately enough can be solved or modified by the input of man-power and money. To define is to settle the limits of, to make clear, to make up the total character of, a phenomenon. It is man's way of bringing light into darkness, order out of chaos. In the presence of mental handicap, however, man is opposed by an unquantifiable, irrational surd. Unable to change it, he can exhaust himself in new ways of defining it, mistaking energy in the latter sphere for success in the former. It remains the case, however, that an attempt at a definition must be made for on that depends our estimate of its prevalence.

There are two ends of the spectrum of mental handicap, pathological and cultural. All those with a measured I.Q. of less than 50 (which includes those in whom no I.Q. at all is discernible) fall within the former group, those with an I.Q. between 50 and 70 comprise the latter group.

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(35) T.L. Pilkington, 1972, The concept and prevalence of mental retardation, 75

The clearest statement of the causes of pathological mental handicap known to this writer occurs in a World Health Organisation pamphlet (36). Causes can occur before conception (genetic and other factors, single gene, extra chromosomes, multifactorial deficiencies and/or imbalances): in the pre-natal period (infections, chemical influences, nutritional-, physical-, immunological-, endocrinological-, and placental factors, intra-uterine hypoxia): in the peri-natal period (asphyxia, birth trauma, prematurity and low birthweight): and at any point in the post-natal period (infections, injuries, chemical/nutritional deprivation, etc.) Taken together, such a medical diagnosis is possible in only one fifth to one quarter of all ascertained mental handicap.

Whilst every person who has written a book or paper on the subject begins with his own definition of mental handicap as seen from his particular profession's viewpoint, we will quote only two; one is technical, the other popular.

> Mental retardation refers to subaverage general intellectual functioning which originates during the developmental period and is associated with impairment in one or more of the following:- 1. maturation; 2. learning; 3. social adjustment. (37)

> A person who is mentally handicapped does not develop in childhood as quickly as other children nor attain the full mental capacities of a normal adult.... (it) affects a person's ability to learn and reason. (38)

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(36) W.H.O., 1968, Organisation of Services for the Mentally Retarded passim

(37) Definition adopted by the American Association on Mental Deficiency in 1959 (based on Heber's definition)

(38) H.M.S.O., 1971, Better Services for the Mentally Handicapped, 2, 3 (4683)

Since Fölling isolated phenyletonuria in 1934, medical research has made considerable advances in an area hitherto "kept out of the academic halls of medical learning .... treated as if it were non-existent" (39). Genetic counselling, amniocentesis and ultrasonic X-ray scanning of foetuses in utero, advice on maternal diet and the dangers of smoking during pregnancy, better obstetric techniques and surgical intervention; these and many more factors help to improve the lot of those born with signal defects and to limit the numbers so afflicted.

Thus far we have offered a definition of pathological handicap, its causes and some of the preventive measures for controlling its incidence, and an estimate that such cases account for only a quarter of all known mental handicap. All the children and adults covered in this section would clearly have an I.Q. of less than 50, and such considerable intellectual subnormality is a "sine qua non" of mental handicap. At the other end of the spectrum of mental handicap, however, debate rages fiercely. Townsend, amongst others, has levelled serious charges against the use of I.Q. as the sole criterion for determing the presence of mental handicap (40). Such tests measure only a limited number and combination of individual abilities; they are only crudely approximate for individual person; performance can improve with coaching and practice; the tests are not culture-free but demonstrably middle-class in bias; they lead to wasted abilities, i.e. they are self-fulfilling prophecies; and so on. Few would

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(39) Kanner, op. cit., 140

(40) Townsend, 1969, op. cit., passim

deny the accuracy of this indictment, but equally few would contest that I.Q. tests in conjunction with other techniques yield a true picture of a child's present and potential abilities.

Turning to the phenomenon of cultural handicap, the ratio of these to the pathologically handicapped was revealed in the 1904 Report and corroborated in the 1929 Wood Report (41). Successively these prevalence surveys disclosed the following numbers and ratios:-

Four point six per thousand were mentally handicapped, of whom six per cent were idiots, eighteen per cent were imbeciles and seventy six per cent were feeble-minded:

Eight point five per thousand were mentally handicapped, of whom four per cent were idiots, eighteen per cent were imbeciles and seventy eight per cent were feeble-minded.

What, then, is this cultural handicap? One of the earliest tables to indicate the background from which this group is drawn appeared in the 1947 Scottish Mental Survey (42). This same survey, incidentally, indicated a slight upward trend in the mean I.Q. of Scotland's population between the years 1932 and 1947. In one way

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(41) Both the 1904 and 1929 Reports (E.O. Lewis the author of the latter) are quoted frequently; Morris, op. cit., Chapter IX

(42) Quoted in Z.A. Stein and M.W. Susser, 1963, The social distribution of mental retardation, 819-820

Father's occupation	No	% High I.Q's	% Low I.Q's (less than 86)
professional	154	66	0
employers of 10+ men	84	46	2
salaried employees	256	46	3
employers of less than 10 men and wage clerks	934	26	6
skilled manual	2392	23	15
semi-skilled manual	1190	15	21
unskilled manual	1132	12	26

this debunked some of the eugenicists' alarmist prophecies; in another way (since the bulk of the mentally defective were institutionalised and unable to procreate) it reinforced their position. Stein and Susser in their study in Salford describe precisely what cultural handicap is vis-a-vis pathological handicap:-

> When careful examination reveals no positive neurological sign or history suggestive of brain damage, and no obvious physical incongruity or metabolic disturbance: when investigation shows no chemical abnormality in the urine, a normal encephalograph, the expected sex chromatin on oral smear and no abnormality of chromosomes: and when there is no other psychiatric disorder, then the diagnosis can be inferred from the social background... a 'clinically normal' child who has a father in manual work, particularly unskilled work, and no siblings in grammar, technical or similar schools, is more likely to be suffering from mental retardation than from cryptic brain disorder. (43)

Why should such parents produce such children? An answer is given in Birch et al, based on a significant study in Aberdeen. (44)

> Such parents ... in a largely Protestant community, where family planning is practicable and is, in fact, practised by a sizeable section of the population, tend to be relatively fatalistic, have low aspirations, feel unable or unwilling to exercise control over their lives and their environment, and to be present- rather than future-oriented.... (this) subculture is rooted in economic insecurity ... inseparable from less skilled manual occupations, attitudes towards education and academic achievement are indifferent if not hostile, and the school may be perceived by the children as an alien environment representing alien values.

The social class distribution of cultural handicap is highlighted in the Aberdeen study. Mild mental subnormality (I.Q. 50-70) was administratively ascertained exclusively in social classes IIIb-V, and in that grouping, four times more often in class V than

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(43) ibid., 819-820

(44) Herbert G. Birch, S.A. Richardson, Sir D. Baird, G. Horobin and R. Illsley, 1970, Mental Subnormality in the Community

class IIIb. Severe mental handicap, on the other hand, clustered significantly in classes I-IIIa, occurring in only nine per cent of class V families.

Hunt (45) attempted to account for the under-performance of children from such backgrounds thus:-

> .... children in larger families, especially those in which children are closely spaced, tend to get less adult care and varied stimulation during the early months than is got by children in smaller families, and especially those in which children are widely spaced.

Kohn (46) hypothesised that:-

> Members of different social classes, by virtue of enjoying (or suffering) different conditions of life, come to see the world differently - to develop different conceptions of social reality, different aspirations and hopes and fears, different conceptions of the desirable.

In the light of their London survey, Tizard and Grad add one more piece to the jigsaw puzzle:-

> Those who have been buffeted by life may find it easier to restructure their expectations and to face hardships as they come ... they are helped and supported by the humanity and solidarity of the social group .... and those in a large family are likely to have had more experience of caring for and supporting dependent members of all kinds.(47)

It was far easier to state some of the preventive measures open to medicine in helping, or controlling the incidence of the severely handicapped, than it is to suggest ways and means of dealing with

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(45) J.M. Hunt, 1961, Intelligence and Experience, 343; quoted in Birch et al, ibid., 88

(46) M.L. Kohn, 1963, Social class and parent-child relationships: an interpretation, Amer. J. Sociol., 68. 471-480; quoted in Birch et al, ibid., 90

(47) J. Tizard and J.C. Grad, op. cit., 84
This quotation may refer to the strengths of the working classes in handling the problems of a severely handicapped child rather than their propensity for producing mildly handicapped offspring.

the culturally handicapped. Education for the parents as well as the children, advice on family planning, budgeting, suitable diet, etc. probably represent the obvious social interventions.

Goffman (48) writes perceptively of society's labelling of certain groups:-

> Stigma involves not so much a set of concrete individuals who can be separated into two piles, the stigmatised and the normals, as a pervasive two-role social process in which every individual participates in both roles at least in some connexions and in some phases of life.

In the case in point, Dexter argues that society is blaming the mildly subnormal for casting doubt on rationality and rightness in themselves. They challenge the whole basis of modern industrialism with its emphasis on material achievement, abstract intellectualism and compulsory equality through education. They cope as independent adults without undergoing the rigours of academic education like the rest of society (49). Further weight is given to this thesis in two American studies, although it must be borne in mind that in America mild mental subnormality extends to I.Q. 85 (15 points higher than in Britain), and how far that fact alone contributes to these writers' guilt and/or indignation is a moot point. The Braginskys administered various psychological tests to high grade defectives and found their scores several points higher than a sample of both the professional and the ancillary staff at the State institution on indices of motivation, role-switching and machiavellian manipulation of lifestyles and goals. After a shrewd insight about society's converting a metaphor into a myth (we treat the mentally retarded "as

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(48) Erving Goffman, 1963, Stigma, 163

(49) Lewis A Dexter, 1964, On the politics and sociology of stupidity in our society, 43-44, IN Howard S Becker, ed., The Other Side: Perspectives on Deviance

if" they are weak, inept, ineffectual and stupid, gradually omitting the "as if" stage until mental handicap becomes a concrete disease state) the authors reach an extreme conclusion:-

> The concept of mental retardation must be discarded entirely. It has no scientific value .. or humanitarian value .. and has led to enormous expenditures of time, effort and money in a useless search for psychic factors when the real problems exist in society. (50)

Edgerton followed up forty eight discharged high grade patients, painting vivid portraits of where and how they are living 'outside', their work, relationships, sex marriage and children, spare time activities, perception and presentation of self, and the practical problems they experience in maintaining themselves in the community. He elaborates on their techniques of "passing" and "denial" and on their exaggerated need for approval, concluding:-

> If we accept the unanimous findings of the behavioural and psychological sciences concerning the fundamental importance of self-esteem for any human being, then we can understand the dilemma in which these former patients find themselves and we can appreciate their achievement in finding what is for them a cloak of competence. (51)

This discussion of cultural handicap has stressed that the means we have of ascertaining the condition (the I.Q. test) is middle-class in bias and perhaps self-fulfilling prophecy; that the

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(50) Dorothea D and Benjamin M Braginsky, 1971, Hansels and Gretels: Studies of children in Institutions for the mentally retarded, 176.
The most telling critique of this extreme case of the baby being thrown out with the bathwater is Hunter's phrase, "If you throw out the pathology you throw out the pathos"

(51) Robert B Edgerton, 1967, The Cloak of Competence: Stigma in the lives of the mentally retarded, 219
This book does more than indicate that most of the mildly handicapped ought never to have been in Institutions in the first place; it indicates the vulnerability of those whom society has once forced to wear "L" plates and then accepted into the traffic flow as having passed the test.

subjects with the condition come from large, poor, working class families whose goals and habits do not necessarily coincide with those responsible for the educational system; that the phenomenon is at least as indicative of something "wrong" with society as with the culturally handicapped; that institutionalisation is not the most appropriate context for them in which to acquire society's standards and ambitions; that, with their mental retardation, they nonetheless enjoy a normal emotional repertoire and can be and often are hurt by living with the sense of failure attributed to them by society.

We close this section with an estimate of the prevalence of mental handicap in toto, pathological and cultural. Approximately two to three per cent of the population of any developed country would be classified as mentally handicapped, three quarters of this number being culturally handicapped. With the difficulties admitted, namely, what concept of mental handicap is chosen at the outset?; what methods of determining its presence are adopted?; what age are the subjects surveyed?; prevalence surveys have been collated in an Office of Health Economics pamphlet (52). In the United Kingdom as a whole, three point seven per thousand in the population of school age are severely mentally handicapped, and across all age groups, there are an estimated one and a quarter million mildly handicapped people. Restricting the immediate concern to Scotland, a 1972 estimate, in round numbers, indicated fifteen hundred severely mentally handicapped pre-school age children, an unknown number of mildly handicapped pre-school age

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(52) Office of Health Economics, 1973, Mental Handicap, 9-10

children; three thousand six hundred severely handicapped and eight thousand seven hundred mildly handicapped school age children; and seven thousand six hundred severely handicapped and nine thousand two hundred and fifty mildly handicapped adults. Across the age groups, the current severely handicapped population totals twelve thousand seven hundred, the mildly handicapped population is seventeen thousand nine hundred and fifty (53).

Our conclusion on the century and three quarters under review is that early optimism and subsequent pessimism have given place to present realism. The leitmotif is growth within limits rather than limitless growth, excellent care rather than eventual cure.

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(53) Scottish Home and Health, and Scottish Education Departments, 1972, Services for the Mentally Handicapped, 2, 38 - 45

Chapter 3 The importance of the family in the care of a mentally handicapped child

> Professionals might be more helpful if they concentrated more on the improvement of institutions than on the enlightenment of parents ... (conversely) when we see problems like mental deficiency abstractly, our feelings may become refrigerated, and then our understanding is likely to be diminished. (1)

This quotation from Olshansky describes the difference in approach between American and British professionals who have worked with parents of mentally handicapped children. In America the emphasis has been on analysing parental reactions on learning of the child's handicap; offering counselling and support at that time and thereafter; harnessing family strengths in adjustment strategies for coping with the strains and stresses generated by the child in the home, and linking afflicted families with each other in group therapy. In Britain the tradition has been to interview parents to discover the use they have made of the available services; to order the priority of their unmet needs, and to expand existing and introduce new provisions. The dichotomy is not absolute, however, for many British studies have revealed a widespread expression of the parents' need of sympathy and understanding, and certain American studies have been geared towards improving the services. It is apparent to us that the two approaches are complementary. Ill adjusted parents will not adjust lastingly better to unchanged facilities. Parents feeling misunderstood and treated with little sympathy will not readily value or use new services.

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(1) Simon Olshansky, 1966, Parent responses to a mentally defective child, 23

How can we account for the differences in the American and British approaches, whilst recognising that both originated in response to expressed parental dissatisfaction? Mental handicap in Britain was given a medical "persona". Most parents do not doubt or deny the competence or concern of their doctor who tells them what is right and in the best possible way. Any subsequent parental dissatisfaction, therefore, must be directed not at the deliverers of the services but at the services themselves. This, then, is the area for improvement. Mental handicap in America was given an educational "persona". Many parents can and do question the manner of handling and success in teaching their child. Any expressed dissatisfaction, therefore, must be aimed at the deliverers of the services and not the services themselves. This, then, is the area for initiative. A Corinthian "better way" would be to seek an inter-professional approach which incorporated the parents as team members, and this we believe to be the significance of recent developments.

This chapter will review most of the relevant British research, but can only select a sample from the treasury of literature from America (and, we should add, Australia and Canada). It is possible that the experience accumulated in countries where counselling has a long history, can be of service in the establishment of such a profession/service in this country. We enter the necessary caveat, however, that it is as false to pretend that the problem consists in a phenomenon in the psyche of parents with a mentally handicapped child, as it is to proceed on the assumption that no parents have ever been injured and abandoned together with their mentally handicapped child.

A British Research on Families

> At the present time the most serious problem for the mother of the very young handicapped child stems from the virtually complete absence of help available to her before the child starts school. This is perhaps the most serious single deficiency of our present services and one that should command a greater degree of professional commitment. (2)

Many studies have touched on the importance of the diagnostic interview en passant, but five have concentrated on this traumatic incident. Drillien and Wilkinson interviewed seventy mothers (whose memories corresponded well with hospital records) who had given birth to a severely subnormal child in Edinburgh between 1950 and 1956. We set out in the footnote the timing and satisfaction ratios, and quote the authors' conclusion:-

> The mothers who spoke most appreciatively about the way they had been told were those who, having been warned or told soon after the birth, were given a full explanation at that time or within the next three months, more especially if thereafter they were encouraged to return to the family doctor or paediatrician with any further queries and were given regular support and advice throughout the early years. (3)

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(2) Peter Mittler, 1972, Education of the mentally handicapped, 155

(3) C.M. Drillien and E.M. Wilkinson, 1964, Mongolism; when should parents be told?, 1307

When told	No.	Satisfied	Dissatisfied
less than 10 days	16	13	3
10 days - 30 days	2	1	1
one - six months	20	12	8
six months - one year	13	7	6
one - two years	9	2	7
two years +	3	3	0

D'Arcy consulted ninety mothers of Mongol children in Liverpool between three and seven years after the child's birth. The majority wanted to know as early as possible; those who had a later diagnosis were more profoundly affected; exceptionally, a few argued that they would have preferred a later interview, on the grounds that 'you should learn to love your baby before you know he is a Mongol'; and all were annoyed if they were not informed simultaneously that besides Mongolism he had another defect (e.g. weak heart). She recommends that the diagnostic interview should be marked by sympathy, clarity, sensitivity to the mothers' questions, and realism rather than the extremes of pessimism or optimism. (4)

Gilderdale and Way asked ninety five mothers of Mongol children living in London, from a wide social background, anything from one to thirty years after the child's birth, what they recalled of the interview informing them of his handicap. Whereas only one mother felt she had been told too soon, twenty one mothers could not decide between an earlier or later telling, and the remainder wanted to know soon after the birth. Five mothers claimed to have been deceived or fobbed off, and what the mothers were told ranged from pessimism through optimism to nonsense. The authors argue that the information should be clear and simple, the available services spelt out, a social worker appointed for ongoing liaison and ideally husband and wife should be told together. (5)

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(4) Elizabeth D'Arcy, 1968, Congenital defects: mothers' reactions to first information, 796-798

(5) Susan Gilderdale and Jean Way, 1969, Your child is a Mongol, 634 ff

Carr reviewed earlier studies and then reported on forty six families in Croydon, evenly spread between social classes I - III Non manual and III Manual - V. Between five and seven in ten were told before seven weeks, a complete seventy per cent by six months, none as late as two years. Nonetheless, forty per cent suspected before they were told; five out of the fourteen told before four days wanted even earlier telling; and five out of forty six wanted later telling to give time to pull themselves together or to be happy longer. Carr makes a strong case for not telling the husband first and making him keep it a secret from his wife. "This seems too heavy a burden to impose and one that a father shouldn't be expected to bear, or anyway, not for longer than a day or two." (6) Together with Oppe, Carr wrote the report of a working party set up by the National Association for Mental Health. Its main points are:- tell as soon as possible and in a way to enable acceptance rather than provoke rejection; expect to encounter grief and guilt in the mother, anger and anxiety in the father; be convinced and convincing in the message, instilling your confidence in the parents' competence; and ensure continuity of information and support (7).

How parents react to the presence in the home of a mentally handicapped child has been documented, for instance, in Schaffer's study of thirty Glasgow families with a pre-school cerebral palsied

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(6) Janet Carr, 1970, Mongolism; telling the parents, 219

(7) J.F. Carr and T.E. Oppe, 1971, The birth of an abnormal child, 1075-77

child. Seen at three-to-four monthly intervals over a period of two years, certain of these families were 'too cohesive'. The mother couldn't leave the child alone for as little as half-an-hour, the fathers were highly involved (in play activities rather than nursing) and the siblings were seen as helpmeets for the handicapped child. Schaffer interprets this as evidence of repressed feelings of hostility in the parents, with the subsequent necessity of continually reassuring themselves regarding the safety of the child. These thirteen 'too cohesive' families scored low on child-rearing practices, were as liable to refuse as to use experts, but never encouraged or reinforced the child. Such parental passivity substantiates the charge of repressed hostility. The parents were acting out an indulgent role whilst by-passing the disciplinary role. Independently assessed by others involved with them, the same children (whose names had been withheld) were judged to be socially immature, overdependent and egocentric (8).

Bentovim has written a perceptive article on child-rearing practices. The infant responds to the amount of warmth, empathy, efficiency and control shown by the mother. The quality of his response (activity or passivity, positive or negative mood, ease of stimulation or difficulty of arousal, etc.) in turn considerably affects her response. Every child, the author argues, enjoys the reassurance of the familiar, but for the child deprived of information about his environment there is the danger that he may cling obstinately to a known and lower level of performance than his siblings. In order that he can grow he needs to experience

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(8) H.R. Schaffer, 1964, The too cohesive family: a form of group pathology, 266-275

frustration and failure, otherwise he becomes over-controlled, over-dependent and infantile. This may occur in relation to bladder and bowel control, even to speech onset and social involvement with persons other than the mother. His conclusion is that such a child "may be convinced that he is always right, maintain his ideas of omnipotence and egocentricity, and prevent the development of empathic appreciation for feelings and needs of others." (9) Parents should be helped to ventilate their feelings by means of crisis intervention on a one-to-one basis, or by means of parents' groups which "can help channel the powerful feelings aroused in the families to constructive, reparative ends ... meeting the needs to do something."

Four mothers each of whom exposed the 'motherhood myth' are portrayed in an article by Wilson. The myth in question is, 'Enjoy your duty'. That, she says, is a mixture of the reality and pleasure principles. In the case of Mrs. S, reality was sacrificed by her denial. Mrs. C sacrificed the retarded child. Mrs. F sacrificed her husband. Everything and everyone was sacrificed by Mrs. A. All displayed guilt feelings and depression, and the author hoped by supporting them to be able to change their neurotic symbiotic patterns. In the event, the author compared unfavourably the frailty of the nuclear family with the solidity of the extended family, arguing that the family itself should be seen as a social institution which could be controlled and changed if wanted. The mothers whose angst was outlined above, were defended by Wilson. Can they be blamed, she wonders, for rejecting

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(9) Arnon Bentovim, 1972, Handicapped pre-school children and their families - effects on child's early emotional development, 634-7

the handicapped child at birth if the reality is that:-

> society, in expecting the isolated mother in the nuclear family to care for a grossly handicapped child, is exploiting the very longing for motherhood it is so anxious to instil or reinforce in all women. (10)

Cornwall County Council was the first authority in Britain to appoint a specialist counsellor of parents with handicapped children, and in a private communication with this writer, Blake shared some of her findings and recommendations. Rejection is atavistic and leads to guilt. Either parent may reject, dependent often on who learns, and how, of the child's handicap. Parenthood can come in one of three phases of married life: young parents with a first baby; middle aged parents with a first baby, and middle-aged parents with a large(r) family. The first two groups of parents, should they produce a mentally handicapped child, are more vulnerable. Blake favours home rather than clinic appointments, recommends teamwork between the professionals involved, and eventual integration of the parents into discussion groups with similarly placed parents. In her view, the counsellor must be female, accessible, unshockable and warm. At some point in the relationship, however, this female counsellor should introduce into the home a male colleague for the sake of the child's father. (11)

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(10) Elizabeth Wilson, 1971, Exploited mothers, 6-7

(11) Pauline Blake, 1972, Rejection - A pattern of counselling, 1-8

The two needs which have recurred time and again in the articles just reviewed are for a sensitive news-breaking interview, and a long-term supportive relationship for the parents. Smithells says of the former, "On the first interview at which the news of the defect is broken, little of what is said is remembered, but the telling makes a deep impression." (12) The type of counselling relationship required is suggested by Cashdan. It should be continuous (as it is with deaf children), regular (though perhaps not frequent) and developmental (current levels and needs related to the total family situation as a guide for future expectations). (13).

Next, we turn to a consideration of research more akin to that carried out in the central part of this thesis. Holt conducted a parental survey in Sheffield in 1957 by means of home interviews of roughly one hour duration, ideally with both parents present. He detected parental attitudes ranging from over-protection through denial, resentment, submission and fatalism to acceptance (this last being very rare). Social isolation, quarrelling and marital separation afflicted the parents' life together, and problems which he specified as avoidable distressed many mothers. Of the two hundred and one families, forty three could not have more children, twenty families were indifferent, thirty eight families wanted more children and one hundred families wanted no more children. Extra expenses were incurred in one third of the families. Social life was curtailed and holidays rare in many families. Far more

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(12) R. W. Smithells, 1969, The management of congenital abnormalities, 432

(13) Asher Cashdan, 1968, Mothers bringing up physically handicapped children, 204, IN J. Loring and A. Mason (eds) The Subnormal Child

families reported that the handicapped child had had adverse effects on his siblings than beneficial effects. He closes his study with the plaintive words, "the parents deserve more consideration and assistance." (14)

Tizard and Grad (15) interviewed two hundred and fifty families in London (one hundred and fifty with the handicapped member at home, one hundred having hospitalised the subject) in 1961. In the home the defective can play the role of a companion to a widowed mother; a family pet; a go-between in an estranged marriage, or a tension-maintainer in a disturbed marriage. Society's attitudes and the disorganisation of family roles are real problems. Within the sample, parents of Mongol children almost unanimously advocated early telling, and of the eighty parents in question fifty five per cent were told poorly or in a way remembered with dissatisfaction. The authors recommend support for families to enable them to keep the child at home, for he can be as loving and responsive to affection as any other child.

Moncrieff (16) developed the findings of Tizard and Grad, hoping to discover the social support required by an adult or near-adult defective; isolate factors requiring long-term support; assess the impact of the 1959 Mental Health Act; determine what services a sample of families had used, and how far the parents' and the Mental Welfare Officer's perceptions of the family's needs coincided.

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(14) Kenneth S Holt, 1957, The impact of mentally retarded children upon their families, 116

(15) Tizard and Grad, op. cit., passim

(16) J. Moncrieff, 1966, Mental subnormality in London: A survey of community care

Of the one hundred and fifty 'home' defectives in the earlier survey, thirty seven had been admitted to hospital between 1957 and 1963, for factors such as incontinence, immobility and speechlessness. More parents kept daughters at home than sons, and more defectives were admitted to hospital from small families than from large families. The mental health of the parents was a significant factor in their decision to hospitalise the child; income and housing adequacy were less significant. "What matters is the kind of help needed on the personal level. Is it simple counselling or more fundamental therapeutic assistance? Is it intensive or is it long-term?" (17) Her recommendations include better managerial and administrative skills in organising the services; research into the causes of the high turnover rate of social workers in the field of mental subnormality, and departmental co-operation between Health, Education and Welfare Departments.

Hewett's study involved assessing the degree of severity of the child's spasticity per se as well as its combination with other defects, general health, etc. Her 'population' was resident in the East Midlands. Parents were asked whether they had been told together or separately; how frequently they had hospital appointments; their estimate of the value of these consultations, and how often they had seen a different doctor. She devotes a section of her book to an illumination discussion of the phenomenon of guilt.

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(17) ibid., 27

Is this guilt experienced by the parents because they produced such a child? because they cannot feel the same way towards him? because they are not doing enough for him? because they are doing too much for him? because they want to send him away? because they want to keep him at home? or because they are neglecting their other children? Insofar as guilt often manifests itself as over-protectiveness, is this device indicative of deep compassion towards the so-deprived child? or of the assuaging of their own guilt? (18) Such a shrewd analysis of the far from monolithic phenomenon of guilt warns the wise of the danger of unexamined cliches and homespun philosophy.

Revans and Baquer pursued three goals in their study. Two hundred and twelve families spread in representative districts of England and Wales were asked their needs; the Mental Welfare Officers involved with these families were asked their assessment of the parents' needs, and the involved Mental Welfare Officers, Health Visitors and family doctors were asked how important was the role of co-ordination in their understanding. The authors posit a "law of involvement" in which "the more handicapped the child, the more active the parent, the more engaged the M.W.O., the more contacts he makes, the higher the level of help received, and of parental satisfaction" (19). Unmet parental needs were pithily summarised as:- We got no advice: We got no help: We got wrong help or advice: We don't see how this person/service can help.

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(18) Sheila Hewett (with John and Elizabeth Newson), 1970, The Family and the Handicapped Child: A study of cerebral palsied children in their homes, 77-78

(19) Reginald W Revans and Ali Baquer, 1972, I thought they were supposed to be doing that, 119

The authors describe in a telling figure of speech "at risk" parents. Like the victims of a ship wreck, there are some survivors who no longer present with a problem and are either more persistent or more resilient than the others. There are some drifters who do not seem able or willing to face the problems realistically. There are some drowners who endlessly repeat, "No one came", and struggle on in fatalistic submission. Lastly, there are some strugglers, outwardly coping but inwardly resigned, in an unstable equilibrium. From this survey the authors report on the value of self-awareness in participative learning attested to by all who took part in it. It brought people together, increased their awareness of other people's problems, led to team building and the overcoming of resentments. Changes were set in motion, and a system which to many within looked impervious to change proved to be 'human'.

In an excellent handbook Parfit (20) has listed the varieties of parental groups which are operating in the country (e.g. informational, instructional, insightful, home-management skills, and so on), and the types of leadership exercised (non-directive, supportive, didactic and interpretative). The author's preference, as we read it, is for the recognition and expression of inner feelings.

The third characteristic of the British studies (besides the diagnostic interview and the ongoing relationship with parents), is the realisation that professionals err if they treat the parents

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(20) Jessie Parfit, 1971, Group work with parents in special circumstances, 1-152

as if they were inept, weak and stupid. On the contrary, by informing, instructing, encouraging and respecting the parents' strengths and desire to further their child's growth, the professionals have made a priceless ally, and the child has gained a revitalised family group.

B Research on Families in Other Countries

> One must make oneself a welcomed part of another, and another a welcomed part of oneself, if help, and especially long-term help dealing with intimate matters, is to be truly helpful... do not deny the retardation, or the future, or the energy and strengths that people possess potentially and actually. (21)

Proceeding in a more or less chronological order, we will review representative studies on the diagnostic interview; the patterns of parental reaction; the meaning of a defective child to his parents; the strategies of marital and familial adjustment; the merits of individual and of group therapy, and factors present in the decision to institutionalise the mentally retarded child. The term 'mental retardation' and its cognates is preferred in American literature. Americans, too, extend the concept of mental retardation to include those with a measured I.Q. of 85. Socio-economic status in America cannot unambiguously 'translate' into British equivalents. The non-British studies also rely more heavily on psychological measuring instruments and the use of mailed questionnaires. Objectivity and therefore replicability are virtually excluded from attitudinal studies, even where standardised tests are utilised. We infer, moreover, that many of the agencies which offer counselling are outwith the financial reach of many parents with mentally retarded children, and a self-selecting wealthy clientele are to that extent unrepresentative of American society as a whole. With these provisos in mind, we will examine the chosen studies. Valentine, a paediatrician, suggests that parents want to know three things: why did it happen? will it happen again? what can be done for my child? If the

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(21) Hans S Falck, 1966, Mental retardation, a family crisis: the role of the social worker, 29, 31; IN C G Chakerian, op. cit.

paediatrician is alert and takes the time to move at the parents' pace, and if he resists the temptation to eradicate all infantilism from the parents, the chances are higher that what is best for the child will be done. Parents who are supported will be supportive. (22) Roos urges that parents should be treated by the professionals with respect. The counsellor should avoid authoritarianism, encourage free emotional expression in the parents, and allow the parents to make decisions regarding institutionalisation, and so on. Above all, the counsellor should be honest and 'present' in the interview. (23) "Why are they seeing me here and now?" he should ask himself, alive to the possibility that the parents, though speaking about penultimate matters may well be preoccupied with ultimate concerns, such as:-

> Existential concern with religion, the meaning of life, the tragedy of death, the inescapability of aloneness, and the relative insignificance and helplessness of man. (24)

Kanner reports a shift in the professionals' concern from merely acquainting the parents of the child's low I.Q. and need for special schooling, to taking the parents' feelings into serious account. Guilt, rebellion, search for causes, matrimonial quarrels, etc. feature in many cases. "There can be over-protection, cold rejection, nagging coercion or open neglect, all defended as legitimate strategies for coping with an accessible, superficial problem." (25)

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(22) M Valentine, 1972, Counselling parents of retarded children

(23) Philip Roos, 1963, Psychological counselling with parents of retarded children

(24) ibid., 347

(25) Leo Kanner, 1953, Parents' feelings about retarded children, 383

Matheny and Vernick in a controlled experiment with forty families at a mental retardation clinic, demonstrated the value of effective communication with the parents regarding the child's abilities and prospects. By questionnaire and interview, before and after the communication programme, parents were asked to estimate their child's present abilities and their expectations of his future. The communication programme resulted in parents tending to assume more realistic school goals; employment goals, and act in accord with these more realistic goals. They conclude:-

> Because of the relatively brief time spent with these parents and because of their significant changes in expectations for and behaviour toward their children, the generalisation that most parents of the mentally retarded adopt neurotic mechanisms must be questioned. It is suggested that the mental retardation clinic place a priority on learning how to communicate effectively with the parents. (26)

From the four studies cited we deduce the importance of not seeing the diagnostic interview as a once-only affair, but as the first of many sessions within an ongoing relationship. The same facts will need to be reiterated until they sink in; a process made the easier if the same person informs and supports the parents.

Of the dozens of articles consulted on parental reaction patterns, we believe that by pruning, we have produced the best fruit. Molony elaborates on a pattern first suggested in an article by Miller (27). Typically, parents pass through three stages:- depression, which includes shame; loss of self-esteem; disappointment; guilt and self-reproach, even masochism: denial, evidenced by denying or ignoring opinions; misunderstanding

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(26) Adam P Matheny and Joel Vernick, 1969, Parents of the mentally retarded child: Emotionally overwhelmed or informationally deprived?, 959

(27) Lee G Miller, 1968, Towards a greater understanding of the parents of the mentally retarded child

instructions or forgetting them; 'shopping around' for a kinder, better diagnosis; search for a magical cure, even delusional beliefs: displacement, in the course of which parents are sensitive to implied criticism, blame spouse, medical and all subsequent personnel, and more damagingly, relate to the child by over-rejection, ambivalence or over-protection. Molony defines these three stages as disintegration, adjustment and reintegration. Her conclusion is apposite:-

> It is necessary to realise that it is not pathological to use psychological defence mechanisms to deal with the very real problem of mental retardation, even though this may result in a deviation from some idealised norm of behaviour, or from romantic notions of 'acceptance.' (28)

Gallagher demolishes another professional 'myth' in much the way that Hewett (see page 76) warned of too glib a use of 'guilt'. 'Rejecting parents' as a concept is re-defined by Gallagher to apply to a relatively small percentage of all parents with a mentally handicapped child. It is not the holding of negative feelings and attitudes as such which constitutes rejection, but rather:-

> The persistent and unrelieved holding of unrealistic negative values of the child to the extent that the whole behaviour of the parent towards that child is coloured unrealistically by this negative tone. (29)

Strong under-expectations of achievement; the setting of unrealistic goals; escape, and reaction formation are four mechanisms of rejection employed by parents. Gallagher distinguished between primary and secondary rejection. The former is pathologically rooted in parental dynamics, its cause the

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(28) Helen Molony, 1971, Parental reactions to mental retardation, 917

(29) James J Gallagher, 1956, Rejecting Parents?, 2

unchangeable nature of the child himself. The latter is more amenable to change, its cause the behaviour manifestations of the child. The author concludes with an appeal to curtail the widespread labelling of parents as rejecting. In their feelings of resentment, downcastness and discouragement from time to time, parents are in fact merely acting like human beings.

Olshansky has coined the term "chronic sorrow" to describe the feelings of parents with a child stigmatized with (Goffman's phrase) "spoiled identities". This chronic sorrow is an understandable, non-neurotic response to a tragic fact which lasts as long as the child lives. Together with this sorrow parents can display guilt and anger; an inverted death wish (censored into the acceptable, if misleading, query, "What will happen to my child when I die?"), and a fervent search for a scapegoat. This last pastime, Olshansky notes, can be indulged in by professionals who, to handle the frustration of their own seeming helplessness, retaliate by accusing the parents of denial or regression. It then becomes easier for the professional to deal with neurotic behaviour in the parents than with mental deficiency in the child. (30)

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(30) Simon Olshansky, 1966, Parent responses to a mentally defective child, 21 - 27

Solnit and Stark offer a psychoanalytic interpretation of what the defective child means to the parents. The birth of such a child, they argue, is a severe narcissistic blow equivalent to a real death. The mother expects a normal child and fantasises an image of it. The birth of the defective child means the loss of the normal child, indeed, is equated with a dead child. When it is born the mother hasn't the time to work through the loss of the expected normal child because the abnormal child requires immediate attention. (31)

Ryckman and Henderson propose the following meanings which any child can have for his parents. The child is a physical and psychological extension of the parents. The child is a means of vicarious satisfaction to the parents. Parents can transcend death through the child. The child can be a personalised love object. The parents' own feelings of worth are met by the dependency needs of the child. Finally, the child creates negative feelings in the parents about the demands and limitations of child-rearing. In the case of a defective child, the parents' self-concept is drastically altered, and can change the way they

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(31) A J Solnit and M H Stark, 1961, Mourning and birth of a defective child in psychoanalytic study of the child. Vol. 16; quoted in Olshansky, ibid., 21

Olshansky levels four devastating criticisms against the psychoanalytical viewpoint of Solnit and Stark. Firstly, the death of a dream child is not equivalent to the death of a real child. Secondly, identification of mental deficiency is often not made at birth. Is it in any sense true or meaningful to describe such parents' reactions to the birth of an as yet unidentified defective as one of mourning? Thirdly, parents who pass through the period of mourning should be free from sorrow. Olshansky's thesis indicates that this rarely or never occurs. Lastly, Solnit and Stark have propounded a theory which keeps the problem neatly encapsulated within the parental psyche when it is clearly both within and outside the psyche.

view the child; even lead to the development of ego-defence mechanisms by means of which they insulate themselves against the threats of the defective child. (32)

Mandelbaum and Wheeler suggest that parents initially react as society traditionally reacts. Then they display defensive or aggressive; protective or punitive, optimistic or pessimistic attitudes towards the child. By the time parents come for help "their inter-relationships are set, as if in concrete..... (however) sometimes their resistance and rebellion (their desire to leave no stone unturned) may be healthy adaptive mechanisms." (33)

The three studies cited above are impressionistic in character, that is, they do not identify the population on whom the conclusions are based. Social class of parents, size of family, severity of child's handicap, etc., are facts which could have been disclosed, in the light of which the validity of the conclusions could be assessed.

More satisfactory studies, vis-a-vis the last criticism, are represented by the next three articles. Cummings, Bayley and Rie compared the effects of the child's condition on two hundred and forty mothers, sixty with mentally retarded children; sixty with chronically physically ill children, sixty with neurotic children, and sixty with healthy children (as a control group). In self-

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(32) D B Ryckman and R A Henderson, 1965, The meaning of a retarded child for his parents: a focus for counsellors, 4-7

(33) Arthur A Mandelbaum and Mary E Wheeler, 1960, The meaning of a defective child to parents, 365, 367

administered tests, the mothers revealed their general feelings of self-esteem; of esteem related to the maternal role; concern about the child's health status; discomfort in caring for the child; trends in child-rearing orientation, and inter-personal satisfactions (with family, child, neighbours, etc.). Mothers of mentally retarded children scored highest on preoccupation with the child. They were least successful in handling anger at their child, and lowest on inter-personal satisfaction with the child. They tended towards possessiveness on the one hand, or detachment on the other hand, in their child-rearing practices. This group of mothers were low on self-esteem regarding their maternal role, but not in general esteem. Their urgent need for guidance and assistance, however, made them over-praise the help offered so as not to alienate potential helping agents. (34)

Rosen interviewed thirty six mothers of retarded children, who had reached that stage of adjustment when denial was not manifested nor a miraculous cure sought. He parallels John Dewey's five Steps in Thinking with five stages in maternal awareness of her child's mental retardation. In Dewey's schema, the first step is feeling a difficulty: the mother's is awareness of the problem. The second Dewey stage is location and definition: the mother's is recognition of the problem. The third Dewey stage is suggestion of a possible solution: the mother's is seeking for the cause. The fourth step in Dewey is development of reasoning regarding the

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(34) S Thomas Cummings, Helen C Bayley and Herbert E Rie, 1966, Effects of the child's deficiency on the mother: a study of mothers of mentally retarded, chronically ill and neurotic children, 595 - 608

implications of the suggestions: the mother's is seeking for the solution. The final step in Dewey is further observation and experimentation leading to its acceptance or rejection (i.e. the conclusion of belief or disbelief): the mother's is acceptance of the problem. Rosen claims that this progression in the mother's adjustment is not affected by her intellectual ability, but it may be by her emotions. He concludes that the medical profession needs enlightenment on the problem of mental retardation as experienced by the mothers, for the public attitude is unkind. To be a parent of such a child is not to conform to social norms. (35)

Gumz and Gubrium apply the analysis of marital roles in Parsons and Bales (36) to families with a mentally retarded child. Instrumental leadership refers to the relations of the family with other social systems; expressive leadership refers to relations within the family unit. Fifty families with a mild-to-moderate mentally retarded child in the two-to-five year old range were interviewed. Outlining more fully the differences between the two types of leadership, the instrumental is oriented towards achieving adaptation, maintaining equilibrium and establishing desired relations to external goal objects; the expressive to maintaining integrative relations between family members and managing tension

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(35) Leonard Rosen, 1955, Selected aspects in the development of the mother's understanding of her mentally retarded child, 522-528

(36) T Parsons and R Bales, 1955, Family, socialisation and interaction in process (New York: Free Press); quoted in E J Gumz and J F Gubrium, 1972, Comparative parental perceptions of a mentally retarded child, 175-180

between component parts of the social system. The three areas selected for analysis were:- their perception of the mentally retarded child; of his extra-familial roles, and of his future roles. In each perception fathers tended to a more instrumental, mothers a more expressive orientation. (37)

The most detailed and substantial work on parental adjustment strategies has been undertaken by Farber in Chicago. In the first project he interviewed two hundred and forty families (mostly from higher socio-economic status), husband and wife separately, and amongst the results the following substantiate most of the sixteen hypotheses posited:- the marital integration of parents with boys at home was lower than that of parents with girls at home: as boys age they progressively disrupt the marriage: marital integration was not significantly related to the mother's estimate of the child's dependency. The family role of the siblings was not affected by the sex of the child nor by the parents' social class: where the child is severely dependent siblings were adversely affected: normal daughters did better when the child was institutionalised, normal sons less well in that circumstance. Catholic homes presented as more supportive than Protestant or Jewish, whether the child was at home or institutionalised. More

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(37) Gumz and Gubrium's work is included in this chapter as an example of a self-evident and consequently lightweight exercise; the soundness of the methodology and the caution of the conclusions merely confirm this writer's judgment.

We recall the warning given us about sermon preparation; 'if you aim at nothing, you are likely to hit it.'

appreciation was expressed when the maternal rather than paternal mother involved herself in the running of the home. (38)

In his second undertaking, Farber applied von Neumann and Morgenstern's Theory of Games and Economic Behaviour to families with a mentally retarded child. A game is a set of admissible moves which, combined in certain ways, result in a resolution of a contest. A move is a single alternative in the set of acts specified in the rules of the game. A play is when players choose a number of these moves (at once or successively) to resolve the contest. Strategy is a specific combination of moves. This time he contented himself with seven hypotheses, tested on two hundred and thirty two Chicago families. The three strategies permissible were to be a child-oriented family; a home-life-oriented family, or a parent-oriented family. Parents using consistently one or other of these strategies exhibited a higher marital integration score than families who were not this consistent. Parents with unfavourable circumstances (e.g. demographic and community factors) scored higher on marital integration when the child was institutionalised. As the mentally retarded child aged, his siblings ceased to be viewed as playmates for him, becoming helpmates for the mother - particularly in the case of the oldest normal daughter (39).

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(38) Bernard Farber, 1959, Effects of a severely mentally retarded child on family integration

(39) Bernard Farber, 1960, Family organisation and crisis: maintenance of integration in families with a severely mentally retarded child

In his third study, Farber demonstrated the correlation between the parents' social class and response to the child. The 'tragic crisis' families see the problems regarding ends, and are mainly middle class. The 'role organisation crisis' families see the problems relating to means, and are predominantly working class. The former group of parents find their aims, aspirations and anticipated 'happy' family life disrupted. Their construct of mental retardation is of an uncontrollable event, and they exhibit ambivalence in their reaction to the child, half-blaming and half-exonerating him. The latter group of parents find the interminable care of the child the crux of the problem. His prolonged 'infancy' and unlikely adulthood interrupt the usual family life cycle, but the situation is controllable by re-organising the system of roles. Four hundred and sixty eight families were surveyed, and some new findings emerged. On balance, the tragic crisis is sex-linked for the father; the role organisation crisis is sex-linked for the mother. Whereas kinship, friendship associations and activity in formal organisations are supportive factors for parents of normal children, they are often escape routes for parents of retarded children. Most parents are more dissatisfied with the poor performance of a retarded boy than of a retarded girl. The decision to institutionalise the child was more common in homes where the mother enjoyed poor health, and amongst high socio-economic class fathers on the one hand, and low marital integration fathers on the other hand. It was a step more commonly desired by all fathers than by mothers. There was, however, a striking reluctance on the part of Jewish families to institutionalise the

child. (40)

There is so much wealth in these studies, that the criticisms levelled by Wolfensberger are unexpected. He claims that the sampling bias in every case was unrepresentative; that relying so often on the mother as sole informant led to distortions; that intuition rather than replicability characterised some of the findings, and that no control groups were used (41). Wolfensberger posits a three-stage development in parental reactions. First comes the 'novelty shock crisis' in which "the crucial element ... is not retardation at all; it is the demolition of expectations." Next comes the 'value crisis' in which "often, the parents' reaction is to a construct in their own minds rather than to an objective state." Last comes the 'reality crisis' when "forces external to and only partially controllable by the parents result in situations that make it impossible, exceedingly difficult or inadvisable for the retarded to remain integrated into the family of the community." Information and support are required at the novelty shock stage; prolonged counselling and therapy during the value crisis, and practical, down-to-earth help when the reality crisis is reached.

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(40) Bernard Farber, 1962, Effects of a severely mentally retarded child on the family, INEE P Trapp and P Himmelstein, 1962, Readings on the Exceptional Child

(41) Wolf Wolfensberger, 1967, Counselling the parents of the retarded, IN A A Baumeister, 1967, Mental Retardation. Wolfensberger's review article is comprehensive, authoritative and well repays reading. He develops his own systematisation on pp. 336-337. His critique of Farber appears in Section 2, The Impact of the Retarded Child upon the Family Unit.

Menolascino, with his colleague in Omaha, Nebraska, has presented a chart of Wolfensberger's schematisation. In this he itemises common parental responses; positive crisis resolutions; negative crisis resolutions, and specific treatment needs in step with the three-stage novelty shock, personal values and reality crises. Menolascino himself suggests that there has been a shift in counsellors' expectations. Formerly they anticipated guilt, currently they encounter more often grief and mourning syndromes. Counselling benefits the four participants in the drama insofar as:- the parents achieve better adjustment by recognising and overcoming their own conflicts: the retarded child experiences better parental acceptance and management: the family unit enjoys more harmonious interactions between all the family members on account of the better relations between the parents and the child, and society benefits because the likelihood of family dissolution, emotional problems and institutionalisation is diminished. (42)

In a much slighter review article than Wolfensberger's, Tretakoff mentions the widening circles of parental focus from 'I'-centredness through child-centredness to community-centredness spelt out by Egg, and quotes the paradigm contained in Kanner, that accepting parents equals normal child; rejecting parents equals aggressive child; overperfectionist parents equals frustrated child, and overprotective parents equals immature child. Tretakoff's own recommendation is that "counselling for the parents of these children is as important as education and

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(42) Frank J Menolascino, 1968, Parents of the mentally retarded: An operational approach to diagnosis and management

training is for the children ... (and) if offered as soon after the diagnosis as is possible, anxiety over bearing an impaired child might be ameliorated." (43)

Stone is reminiscent of Tillich in her language describing how minimal, partial and considerable awareness of the child's handicap determine like degrees of acceptance. Parents identify themselves so closely with the child that they feel a part of themselves is defective. They feel, moreover, that they are being mutilated or punished for some real or imagined failure. For such parents, unconditional love is difficult when social pressures in a competitive society imply that a child who is not up to par or is incompetent does not deserve what the parents are constrained to show him. (44)

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(43) Maurice Tretakoff, 1969, Counselling parents of handicapped children: a review, 31; quoting works by Maria Egg, 1964, When a child is different: A basic guide for parents and friends of mentally retarded children (New York: Day). Leo Kanner, 1962, Child Psychiatry (Springfield, Ill: Thomas) 3rd edn., 131

(44) Marguerite M Stone, 1948, Parental attitudes to retardation. Forty four parents comprised the sample population. Twelve showed considerable awareness, twenty one showed partial awareness and eleven minimal awareness at the diagnostic interview. Following psychological tests and remedial teaching tests on the child, the parents were recalled for an interpretative interview. Nineteen demonstrated considerable acceptance, twenty manifested partial acceptance and only five displayed minimal acceptance. She concludes that what the worker knows, and what he is, help the parents to change.

It is in her use of acceptance and unconditional love that the influence of Tillich is evident. These are two of that theologian's key concepts in his systematisation of a theology grounded in God's acceptance and unconditional love "in spite of" man's inner estrangement and impediment.

Mahoney makes the timely reminder that "parents of mentally retarded children are as normal, as average, as maladjusted, as neurotic as are all parents - before the birth of a mentally retarded child." The manifestation that he calls pathological occurs in parents who get "a purpose in life" or "a cause to fight for" in which the child becomes a necessity for a crippled parent. "Experienced first as a threat, he is later incorporated as a crutch." (45)

Schild differentiates two phases in parental adjustment, 'deviance crisis' and 'chronic strain crisis.' In the first phase, parents are expected to cope with their emotional problems. They are expected to accept the reality of the situation sufficiently to engage in needed problem-solving activity on behalf of the child or family. Moreover, they must understand and alter, if need be, their attitudes about mental retardation. In the second phase, they must come to terms with the alteration of their usual parental role in meeting the needs of the retarded child. They must cope with the ways in which the retarded child is influencing and changing inter-familial roles. Lastly, regardless of their self-perception, the parents must recognise that they depend on external support to meet the child's needs, and maybe their own. Throughout these phases, "it is the client's responsibility in the counselling process to reach his own solutions with the counsellor's knowledge used as a means of stimulating the problem-solving process." (46)

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(45) Stanley C Mahoney, 1959, Observations concerning counselling with parents of mentally retarded children, 81, 86

(46) Sylvia Schild, 1971, Counselling services, 282, IN Richard Koch and James C Dobson, 1971, The mentally retarded child and his family (New York: Brunner/Mazel)

Counsellor qualifications are listed by many writers, and salient features which recur are the need for preparedness of self and mastery of facts before the interview, honesty, clarity and sympathy. Feed-back is seen as another necessary component in the client-counsellor relationship. Falck, writing as a social worker, says convincingly, "How I handle myself with the families is much more revealing than how I handle the family." (47)

Group counselling is advocated by Kaplan and Williams, who describe sessions between parents, trainee social workers and professionals. (48) They conclude, "It is the authors' belief that a time is reached in group counselling when one must consider that the group has reached a saturation point with respect to what further gains in knowledge, understanding and attitudinal changes can be achieved. At this point it would be wise to test the relative strengths attained by each parent in his quest to stabilise his family milieu."

Two studies compare directly the feelings and thoughts of parents who have kept the mentally handicapped child at home, with those of parents who have institutionalised the child. Caldwell and Guze studied sixteen 'Home' and sixteen 'Institutional' mothers in St. Louis whose children were matched on many variables. Mothers in the Institutional group did not score higher than the Home group on guilt and rejection. The Home mothers, they point out, are potentially Institutional mothers. The authors conclude:-

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(47) Hans S Falck, op. cit., 29

(48) S Kaplan and M J Williams, 1972, Confrontation counselling: A new dimension in group counselling, 114-115

> The interviewer was impressed by the nearly universal courage, strength and adaptability of these mothers. There was the general impression that as a result of their experiences, nearly all of the women were more sensitive and sympathetic to people with all kinds of problems and handicaps. (49)

Skelton conducted a survey in Toronto of ninety Institutional parents and thirty eight Home parents, matched once more by the age, sex, and degree of handicap of the retarded child. Two questions were asked, "What is your greatest concern?" and "What are the two other most urgent problems?" Seven areas were common and in the same rank order to both groups of parents. (50)

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(49) Bettye M Caldwell and Samuel B Guze, 1960, A study of the adjustment of parents and siblings of institutionalised and non-institutionalised retarded children, 851

(50) M Skelton, 1972, Areas of parental concern about retarded children, 38-41. The findings are given below, in the rank order common to both I(nstitutional) and H(ome) groups.

1. training and education needed for the retarded child
   H = 42%; I = 23%
2. retarded child interfered with family life
   H = 22% (largely aggressiveness); I = 25% (largely nursing needs)
3. other family problems interfered with ability to care for the retarded child
   H = 8%; I = 19%
4. physical care and protection sought for the retarded child
   H = 11%; I = 17% (decision linked with amount of care needed more exactly than with degree of physical or mental handicap)
5. a living situation sought for the retarded child
   H = 11%; I = 11% (parents unwilling to 'lumber' children)
6. recreation and companionship sought for retarded child
   H = 5%; I = 3% (some wanted him to be 'amongst his own kind')
7. retarded child causes problems in the community
   H = 0%; I = 4%

This significant study closes with the analysis that Institutional families displayed significantly greater concern for the welfare of the family:
Home families showed significantly greater concern for the welfare of the child.

It is apparent from reading these studies from other countries that the parents in mind have been those with more severely handicapped children. The particular emotional needs they betray or present; the adjustment strategies they adopt; the types of help most appropriate and the training of counsellors, and factors in the decision to institutionalise the child - all these have been given a fair hearing. What of the culturally handicapped? Since America labels as mentally retarded children with an I.Q. as (relatively) high as 85, what sort of research has been directed towards prevention or intervention in this subgroup? We have discovered only one article, that by Begab. (51) He notes that inadequate parents tend to be less achievement-oriented; less guilty; less low in self-esteem, and tend not to be disappointed or anxiety-ridden about the future. Indeed, the child's mental retardation is often the least of the whole family's problems. They suspect and distrust agency intervention, perhaps because too often they have been confronted with their failures as wage earners, parents and citizens. They become social isolates. They have little knowledge of either mental retardation or of child-rearing practices. Their child, Begab argues, needs to be protected from such a harmful environment. If this is not to be accomplished by separating the child from his family, it must be attempted by training the parents in home-making, budgeting and child-rearing. Sowing seed on such prepared ground, self-awareness and capacity for change can even flourish in such families. He concludes:-

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(51) Michael J Begab, 1964, Counselling parents of retarded children

> As they master the tools for social survival and achieve success in areas of former failure, they may gain in self-confidence and pride, take greater interest in their surroundings and assume a more active role in community life. (52)

Before attempting a summary of this chapter, we make one further quotation.

> Even more broadly, we see the problem of a family dealing with a retarded child, and all it means to them, as one instance of a universal experience, i.e. how a family copes with unexpected disappointment and trauma.... mental retardation does not represent a unique set of problems unrelated to all other mental situations. (53)

This sets the problem in its proper perspective, we believe. The problem for a family is real, it is lasting, it is distressing, but it is not "sui generis", not discrete from all other human experiences. How the parents learn of the child's handicap is of crucial importance. If that initial interview is badly handled, and if the parents are not incorporated into an ongoing relationship at the outset, then problems pile up alarmingly. The counselling can be accurate communication of information; hints and tips in child-rearing practices; individual or group psychotherapy with the focus on the parents' feelings towards the child, or a more profound analysis of parents' feelings only indirectly related to the child. Doubtless many more aims could be listed. There are points for and against a clinic appointment approach, as there are for one based on domiciliary consultations. The level to which the counselling penetrates will differ according to parental need and professional skill. All the pointers are that counselling directed towards 'growth-enabling'

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(52) ibid., 5

(53) Frances Kaplan, 1969, Siblings of the retarded, 207-208

is infinitely preferable to counselling aimed at 'problem-solving'. This last activity must be performed by the parents, not the counsellors.

Once more we take up the point mentioned at the outset. The British approach which seeks to reform services which are admitted to be inadequate, and the American approach which seeks to support parents who are recognised to be vulnerable are opposite sides of the same coin. A marriage of these two will probably be harmonious and fruitful. Need is indivisible and help must be integrated. We believe that an expansion of counselling services in this country would benefit the parents, and as a consequence the child, and his siblings.

Chapter 4 A survey of parental attitudes, experiences and needs in families with a mentally handicapped child in Edinburgh and West Lothian

A Introduction

Whilst it was clear at the outset that there were lacunae in the provision of services for the mentally handicapped in Edinburgh and West Lothian we were impressed with the postulate that it might be differential use (by social class) or failure to use the existing services which prompted some of the criticisms coming from parents' and voluntary organizations.

We considered that social class, degree of mental handicap and family size would be critical factors in determining attitudes, experiences and utilization of services. A schedule was specially constructed so that analysis of its one hundredand four items would yield information on three areas of interest and concern (Appendix A is a copy of the interview schedule). In the first place, what are the greatest needs of parents, at what time are these needs most urgent and what pointers are there as to the best means of meeting these needs? Secondly, what factors seem to determine the utilization or non-utilization of the available services? Finally, what light, if any, would the results of this survey shed on the phenomenon of subcultural handicap?

B Materials and Methods

This survey approximated to a point prevalence survey in the sense that we sought all children ascertained as mentally handicapped and known to the Education authorities (and exceptionally known to the Social Work departments and the voluntary societies) in January, 1972. The prescribed age range was three to eight years.

Edinburgh School Health Service wrote direct to all parents whose children were assessed as handicapped and would attend or were attending Special Schools, Junior Occupation Centres or the Day Centre. There were very few refusals at this stage to the proposed interview. The parents who did not reply were visited by the Health Visitor, and the majority agreed to collaborate. The names and addresses of parents who signed a consent form for teacher or Health Visitor were then sent to the researchers.

It soon became evident that we would be short on children with severe physical handicap in addition to their mental handicap. Accordingly, we were given the names of parents with children at the Murrayfield Day Centre (run by the Scottish Council for the Care of Spastics) and parents living in Edinburgh and West Lothian with a profoundly handicapped child resident in Gogarburn Hospital.

West Lothian Medical Officer of Health sent us the names of children attending a Junior Occupation Centre run by the Social Work Department. The Education Department sent us the names of children attending Special Classes attached to ordinary schools within the county. In all we received the names of one hundred and fifty five families. We wrote a standardised letter (see Appendix B) inviting ourselves to their home for an interview inquiring into their needs and experiences. With the refusals noted hereunder and one discarded interview, there were one hundred and forty four interviews, ninety seven in Edinburgh and forty seven in West Lothian.

Table 1 Interviews planned but not conducted

Reason		Number
Refused Health Visitor's initial request	The identity of these parents not known to researchers	1
Refused Teacher's initial request		2
Refused Researchers' written inquiry (See notes a, b and c)		3
Refused on doorstep after earlier written agreement (note d)		1
Family 'Not known at this address'		4
Family 'Out' on three pre-arranged and agreed visits		2
Total		13

a) "My child is not mentally handicapped but physically handicapped. You have been given the wrong information and I intend to see Dr. X to find out why."

b) "My child has just been tested and is nearly up to her own age group. She is attending the special class in Y school, therefore I don't think it is necessary for her to be examined again. Thank you for the interest shown in L."

c) (Telephone message from distraught mother with a child on the waiting list for Gogarburn Hospital as relayed by the doctor involved with the family).... Mrs. X is very anxious, she cannot see you on the date and time suggested, cannot see you later, cannot see you at weekends; and her husband is not there in the day-time.

d) Father said on the doorstep, "My child's not crippled or handicapped. I know she goes to the school down the road, but she's not as bad as many. There's no point in coming in. My wife is out just now, but said you might as well see us. I don't agree."

In these four cases we decided not to press our desire to interview the parents; strenuous efforts failed to trace the present whereabouts of the four families who had moved unknown to the housing authorities, and the cost in time and money in writing and driving to the last two families outweighed the usefulness of pursuing the matter further. We discarded one interview immediately after it had finished and on reflection a week later. Despite all our efforts to narrow down the field of inquiry, every other answer referred to a different child in a large family with retarded parents and children.

Before the first interview we were fully briefed on administering the schedule and given a set of instructions for our guidance. We conducted each interview with no prior knowledge of the medical or psychological diagnosis of the child. The first interview took place on 14th February, the last on 20th October, 1972, all in the home of the family concerned. As a rule we interviewed two families each evening, although a few day-time interviews were arranged to suit domestic plans, shift-work considerations, etc. The first one hundred and thirty six interviews were jointly conducted, but one researcher returned to America earlier than anticipated thereby missing the last eight. This writer asked the questions in Sections I, III and V, his colleague the questions in Sections II and IV. The former made extensive notes of parents' comments, the latter noted many items of non-verbal behaviour. Each recorded all parental responses.
Each week the researchers spent a day comparing their scores on the previous week's interviews. This was near enough in time for the feeling impact of each interview to be recalled but distant enough in time for a more objective assessment to be reached. After deliberating on any divergent scores and disclosing the grounds for our respective decisions, the researchers arrived at a consensus on the scoring and produced from each pair of original schedules a composite schedule. At the end of the project we compared the first twenty five pairs of original schedules. It was felt that the earliest interviews (before we had become accustomed to the schedule or each other's technique) would reveal the divergence at its greatest. The table hereunder makes apparent the high degree of inter-rater reliability.

Table 2 Inter-rater reliability in an analysis of the first twenty five pairs of original completed schedules

There are 124 columns per schedule but 33 of them were excluded because no differences occurred in them and no parameters could be drawn (e.g. Interview code number, number of children, date of birth, birthweight, mother's/father's age now/at birth of child, etc.) Thus we compared 25 schedules with 91 columns and 498 choices apiece.

No. of columns compared	2275	No. of choices compared	12450
No. of column differences	65	No. of choice differences	301
Percentage of column differences	2.85	Percentage of choice differences	2.42

Many of the choice differences, insignificant in themselves, were resolved in the consensus scoring and finally absorbed in the conflation of tables necessary for Chi square analysis. In the schedules compared above the choice differences were distributed in the following ratios in the eventual composite schedules:- agreement with Witcher's original score, 33%; agreement with Wood's original score, 37%, different to either original score, 30%.

The composite schedules were handled by the South Eastern Regional Hospital Board Data Processing Unit. The data was transferred on to punch cards and analysed on the computer using a specially designed programme. We used a number of what we predicted would be key factors and analysed every column against these items. The key factors were:- age of child, birthweight of child, sex of child, place of residence, social class, mother's present age, ordinal position of child, degree of mental handicap of child, handedness of child, mother's relationship to child, mother's family size plans, parents' assessment of ability to cope and interviewers' assessment of parental coping ability. The final factor was external to the

schedule and ascertained only some weeks after the last interview had been completed, viz. the psychologist's assessment of the child in terms of his proposed educational placement.

The print out produced 1414 tables and much of the work was to exclude tables which were either symmetrical in distribution or revealed an asymmetrical result which was clearly artefact or irrelevant. The Chi square test was performed on all remaining asymmetrical tables with a five per cent level of confidence accepted as the threshold.

C Results

In presenting the results we have decided to work systematically through the questionnaire as administered to the parents. We may thereby lose a certain tidiness of presentation and disclose a number of contradictions. However, it was the researchers' experience that some parents accepted us, saw where we were going and felt free to be frank in their answers only as the interview progressed. On balance, we prefer that witness to the parents' attitudes to stand rather than impose a retrospective pattern indicating the researchers' aptitudes. Two instances of what is at issue are given next. The totals of incontinent children differ as between the answers to Question 20 and Question 90. The numbers denying or suspending judgment on their child's handicap now (Question 18) bear little relation to the numbers who react at present to the fact of his handicap by denial (Questions 45 and 46). In each of these examples a more positive and ?honest response occurred later in the interview. The five sections are concerned with data on the family, data on the child, parents' past experiences and reactions, present situation and needs met and coping, hopes and fears for the future.

SECTION I DATA ON THE FAMILY

1. Age of Child	No.	Per cent.
6 years and over	100	69.4
4 - 5 years	35	24.3
Less than 4 years	9	6.2

Mean age: 6 years 4 months

The youngest child at the time of the interview was one year 4 months, the oldest 9 years 3 months. Taking June 1972 as the midpoint of the survey, the mean age was 6 years 4 months.

TABLE 1 - 1 MOTHER'S RELATIONSHIP TO CHILD BY AGE OF CHILD

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
6 and over	17	21	62	100
Less than 6	13	14	17	44
Total	30	35	79	144
	P = N.S.		X^2 = 6.3343	

Table 1 - 1 analyses the child's present age by the mother's relationship to him; 62% of mothers with children aged 6 and over were regarded as accepting.

TABLE 1 - 2 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY AGE OF CHILD

	More handicapped	Less handicapped	Not tested	Total
6 and over	39	49	12	100
Less than 6	15	6	23	44
Total	54	55	35	144
	P = less than .01		X^2 = 30.5896	

Table 1 - 2 analyses the psychologist's assessment of the child's handicap in terms of the proposed educational placement by the present age of the child. By the nature of the study one would expect that more of the severely handicapped children would be diagnosed before entering school, and the majority of children over 6 years old would be in the less handicapped category and this is clearly shown in the table.

2. Birthweight of Child	No.	Per cent.
Less than 4.15 lbs	11	7.6
5 lbs - 6.15 lbs	58	40.3
7 lbs - 8.15 lbs	59	40.9
9 lbs and over	7	4.9
Not known	9	6.2

No significant findings were adduced from this question, although 10 of the 11 babies (91.9%) of less than 4.15lbs birthweight were either assessed as more handicapped or not assessed at all by the psychologist. There was random distribution on other correlates.

3. Sex of Child	No.	Per cent.
Male	96	66.7
Female	48	33.3

Of the nine children under 4 years of age, eight were boys and by virtue of being diagnosed already, in the more handicapped category. Moreover, five of the six 'only' children were boys. Consequently we noted - and discuss under Question 102 - those families in which the handicapped child is the only son. All nine of the children resident in Gogarburn Hospital are boys.

4. Place of Residence	No.	Per cent.
Edinburgh	97	67.4
West Lothian	47	32.6

TABLE 4 - 1 DISTRIBUTION BY CITY WARD (EDINBURGH) BY PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT

City Ward	More handicapped	Less handicapped	Not tested	Total
St. Giles	1	1	0	2
Holyrood	0	1	0	1
George Square	1	2	0	3
Newington	2	2	0	4
Liberton	11	4	2	17
Morningside	1	1	0	2
Merchiston	1	0	0	1
Colinton	5	2	0	7
Sighthill	4	7	1	12
Gorgie/Dalry	2	0	0	2
Corstorphine	4	1	3	8
Murrayfield/Cramond	1	1	0	2
Pilton	1	5	2	8
St. Bernards	1	0	1	2
St. Andrews	0	0	0	0
Broughton	0	2	0	2
Calton	0	0	0	0
West Leith	1	1	0	2
Central Leith	1	0	0	1
South Leith	0	0	0	0
Craigentinny	4	1	1	6
Portobello	1	3	0	4
Craigmillar	1	9	1	11
Total	43	43	11	97

Table 4 - 1 analyses the distribution of families in City Wards in Edinburgh by the psychologist's assessment. The table reveals the expected picture of Liberton, Sighthill and Craigmillar, but the very slight representation of Leith is surprising. The sample we interviewed fell within a narrow age-range, and figures for all those receiving special education from 5 - 16 years of age might produce the anticipated overall picture. The figures are too small for generalization, but we noted that five of the six 'only' children are in Edinburgh. In part this could be due to quicker diagnostic facilities in the city as compared with rural areas, in part to the administrative machinery within West Lothian County Council. We received names from both the Education and Social Work Departments and not all the names on the second list were known to the psychologist; this accounts for the fact that 68.6% of the not tested children were from West Lothian. The placement of the group of 35 not tested children appears in tabular form under Question 103.

5. Father's Present Age Groupings	No.	Per cent.
Less than 26	3	2.1
26 - 35	49	34.0
36 - 45	56	38.9
46 and over	32	22.2
Not known	2	1.4
Deceased (one aged 28, one aged 50)	2	1.4

Mean age: 39.44 years

One mother refused to say anything about the father of her child except that it was not her present husband, the other claimed not to know the age of her child's father in a marriage lasting only six weeks.

6. Social Class (Registrar General's Classification of Occupations, 1971 Census)	No.	Per cent.
Class I	7	4.9
Class II	17	11.8
Class III	55	38.2
Class IV	23	15.9
Class V	15	10.4
Other	27	18.7

In the 'Other' category there were, besides the two deceased men, one who was in the Armed Services and 24 who were currently unemployed. Inadvertently we failed to ascertain the nature of their last employment and could not therefore group them with the Class V fathers, although the overwhelming majority of them 'belonged' there.

TABLE 6 - 1 HANDEDNESS OF CHILD BY SOCIAL CLASS

	Left/Both handed	Right handed	Total
I - II	13	9	22
III	25	30	55
IV - V	13	22	35
Other	6	21	27
Total	57	82	139

Excluded from this and all subsequent tables by handedness are five children (all in Gogarburn Hospital) described by their parents as having "no grip."

P = greater than .05 $X^2 = 7.5778$

Table 6 - 1, social class by handedness of child, shows that Class IV, V and Other families have a preponderance of right handed children but the differences do not reach significance at the 5% level.

TABLE 6 - 2 PARENTS' ASSESSMENT OF ABILITY TO COPE BY SOCIAL CLASS

	Not well + or - stress	Well + stress	Well - stress	Total
I - II	1	11	12	24
III	0	22	33	55
IV - V	5	13	20	38
Other	2	10	15	27
Total	8	56	80	144

P = N.S. $X^2 = 0.8715$

Table 6 - 2, social class by parents' own assessment of their coping ability with or without stress shows no correlation between these factors.

TABLE 6 - 3 DEGREE OF MENTAL HANDICAP OF CHILD BY SOCIAL CLASS

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
I - II	5	13	6	24
III	24	25	6	55
IV - V	16	12	10	38
Other	16	9	2	27
Total	61	59	24	144

P = greater than .05 $X^2 = 12.5648$

Table 6 - 3 analyses parents' assessment of degree of mental handicap in the child by social class. There is a tendency for Classes IV, V and Other to deny handicap or express themselves as unsure, 49.2% of them coming in this category.

TABLE 6 - 4 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY SOCIAL CLASS

	More handicapped	Less handicapped	Not tested	Total
I - II	13	9	2	24
III	17	21	17	55
IV - V	16	8	14	38
Other	8	17	2	27
Total	54	55	35	144

P = less than .01 X^2 = 19.4734

When the psychologist's assessment is analysed by social class (Table 6 - 4) there is an analogous tendency for Classes I and II to have the highest proportion of severely handicapped children, whilst Classes IV, V and Other show a preponderance of less handicapped or not tested children.

7. Father's Present Health	No.	Per cent.
No complaints or disabilities	107	74.3
Complaints only	8	5.6
Complaints and disabilities	15	10.4
Not known	12	8.3
Deceased	2	1.4

In the 'Not known' category the 12 men had separated from or divorced their wives. The 'Ill' fathers comprised only 15.9% of the total and no significant findings can be adduced from so small a number. We took medical advice as to which category was indicated by the specific health problems reported to us in answer to this question, Question 10 (on the mother) and Question 21 (on the child).

8. Mother's Present Age Groupings	No.	Per cent.
Less than 26	3	2.1
26 - 35	67	46.5
36 - 45	56	38.9
46 and over	18	12.5

Mean age: 36.44 years

As compared with the father's present age groupings, there are 18 more mothers in the 26 - 35 age group and 14 fewer in the 46 and over age group.

TABLE 8 - 1 MOTHER'S FAMILY SIZE PLANS BY MOTHER'S PRESENT AGE

	No effect	No more children	Other	Total
Under 35	42	19	9	70
36 - 45	32	20	4	56
46 and over	13	4	1	18
Total	87	43	14	144

P = N.S. $X^2 = 3.0958$

In the 'Other' category are two widows, five mothers who wanted another child to make up for the handicapped child, and seven mothers who had been sterilised.

Table 8 - 1 analyses mother's family size plans by her present age; 29% in the 26 - 35 age group and 35% in the 36 - 45 age group wanted no more children, and 5% in these two age groups taken together had been sterilised. In the 46 and over age group 72% of the mothers claimed that the handicapped child had had no effect on their family size plans and all but two of these mothers had in fact completed their families with the birth of the handicapped child.

9. Mother's Job	No.	Per cent.
None	106	73.6
Part-time job	31	21.5
Full-time job	7	4.9

The numbers are too small for significant comment; however, five of the seven mothers in full-time work have a child who has been assessed as more handicapped by the psychologist, three of these seven mothers have an under 5 year old child, and only two of the seven mothers have their child in Gogarburn Hospital.

10. Mother's Present Health	No.	Per cent.
No complaints or disabilities	105	72.9
Complaints only	27	18.7
Complaints and disabilities	12	8.3

TABLE 10 - 1 SOCIAL CLASS BY MOTHER'S PRESENT HEALTH

	I - II	III	IV - V	Other	Total
No complaints or disabilities	18	44	27	16	105
Complaints only	2	9	10	6	27
Complaints and disabilities	4	2	1	5	12
Total	24	55	38	27	144

P = greater than .05 X^2 = 12.2901

There is a tendency for mother's ill health to cluster in Classes IV, V and Other (Table 10 - 1) but the differences are not significant.

TABLE 10 - 2 MOTHER'S FAMILY SIZE PLANS BY MOTHER'S PRESENT HEALTH

	No effect	No more children	Other	Total
No complaints or disabilities	65	32	8	105
Complaints only	16	8	3	27
Complaints and disabilities	6	3	3	12
Total	87	43	14	144

P = N.S. $X^2 = 3.7807$

Family size plans show no correlation with mother's present health (Table 10 - 2).

TABLE 10 - 3 PARENTS' ASSESSMENT OF ABILITY TO COPE BY MOTHER'S PRESENT HEALTH

	Not well + or - stress Well + stress	Well - stress	Total
No complaints or disabilities	39	66	105
Complaints only	18	9	27
Complaints and disabilities	7	5	12
Total	64	80	144

P = less than .02 $X^2 = 8.6046$

Mothers currently in good health show a trend for coping well without stress as judged by the parents themselves (Table 10 - 3).

TABLE 10 - 4 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY MOTHER'S PRESENT HEALTH

	Not well + or - stress	Well + stress	Well - stress	Total
No complaints or disabilities	8	53	44	105
Complaints only	5	15	7	27
Complaints and disabilities	1	9	2	12
Total	14	77	53	144

P = N.S. $X^2 = 6.8204$

Likewise, mothers currently in good health show a trend for coping well without stress as judged by the interviewers (Table 10 - 4).

TABLE 10 - 5 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY MOTHER'S PRESENT HEALTH

	More handicapped	Less handicapped	Not tested	Total
No complaints or disabilities	34	43	28	105
Complaints only	13	7	7	27
Complaints and disabilities	7	5	0	12
Total	54	55	35	144

P = N.S. $X^2 = 7.4361$

Again, there is a trend, but no significant differences, in the correlation between more handicapped children in the psychologist's assessment and mothers with more symptoms or disabilities (Table 10 - 5).

TABLE 10 - 6 MOTHER'S RELATIONSHIP TO CHILD BY MOTHER'S PRESENT HEALTH

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No complaints or disabilities	22	21	62	105
Complaints only	5	11	11	27
Complaints and disabilities	3	3	6	12
Total	30	35	79	144

P = N.S. $X^2 = 5.3419$

Mothers judged to be ambivalent or rejecting in attitude tend to have more complaints or disabilities (Table 10 - 6).

11. Psychiatric Illness in Father's Family	Home	Hospital	No.	Per cent.
None			85	59.0
Child's grandparent(s)	8	4	12	8.3
Child's uncle(s)/aunt(s)	8	4	12	8.3
Child's father			5	3.5
Other relative(s)			6	4.2
Not known			24	16.7

12. Psychiatric Illness in Mother's Family	Home	Hospital	No.	Per cent.
None			106	73.6
Child's grandparent(s)	4	3	7	4.9
Child's uncle(s)/aunt(s)	7	7	14	9.7
Child's mother			10	6.9
Other relative(s)			7	4.9

Taking these two questions together we recall them as being amongst the most quickly and negatively answered in the interview. We

seemed to be touching a raw nerve and often came away from homes feeling that we had incomplete information. Admitting to the seeming stigma of a family history of mental illness and to having a mentally handicapped child in the presence of two complete strangers whom they would see only once is perhaps a sufficient explanation of this subjective judgment by the interviewers.

In the case of the fathers no statistical significance can be claimed because of the absence of a quarter of the fathers. The mothers were more forthcoming, a few of them mentioning their own post-puerperal depression which they claimed was aggravated if not occasioned by their reaction to the early diagnosis of the baby's handicap.

TABLE 12 - 1 MOTHER'S RELATIONSHIP TO CHILD BY PSYCHIATRIC ILLNESS IN MOTHER'S FAMILY

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
None	22	27	57	106
Child's grandparent(s)	3	1	3	7
Child's uncle(s)/ aunt(s)	2	2	10	14
Child's mother and/or other relative	3	5	9	17
Total	30	35	79	144

P = N.S. $X^2 = 4.0281$

More research might explain the attitudes of mothers who admit to a family history of mental illness, deny their child's handicap as a concept yet behave acceptingly towards their child as a person. Table 12 - 1 indicates that 57.8% of mothers acknowledging a family history of mental illness were judged to be accepting towards their child.

13. Number of Children now alive in Each Family	No.	Per cent.
One - three	90	62.5
Four - six	42	29.2
Seven or more	12	8.3

Mean number of children per family: 3.60

There were six families with an only child and one family with 14 children; the mean number of children per family was 3.60.

TABLE 13 - 1 ORDINAL POSITION OF CHILD BY NUMBER OF CHILDREN NOW ALIVE IN EACH FAMILY

	Oldest/Only	Youngest	Middle	Total
One - three	30	42	18	90
Four or more	3	24	27	54
Total	33	66	45	144

P = less than .01 X^2 = 21.1192

Whilst there was found to be no correlation between family size and social class, there was a tendency for handicapped children who were 'middle' children (i.e. not only, oldest or youngest) to come from larger families; 64.3% of middle children came from families with four or more children (Table 13 - 1).

TABLE 13 - 2 HANDEDNESS OF CHILD BY NUMBER OF CHILDREN NOW ALIVE IN EACH FAMILY

	Left/Both handed	Right handed	Total
One - three	43	43	86
Four or more	14	39	53
Total	57	82	139

Excluded are the five Gogarburn Hospital children with "no grip"

P = less than .01 X^2 = 7.5393

There was a highly significant tendency for right handed children to come from larger families (Table 13 - 2).

TABLE 13 - 3 MOTHER'S RELATIONSHIP TO CHILD BY NUMBER OF CHILDREN NOW ALIVE IN EACH FAMILY

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
One - three	23	23	44	90
Four or more	7	12	35	54
Total	30	35	79	144
	P = N.S.		X^2 = 4.3415	

Accepting maternal attitudes linked with larger families, almost two thirds (64.8%) of the families with four or more children having an accepting mother (Table 13 - 3).

TABLE 13 - 4 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY NUMBER OF CHILDREN NOW ALIVE IN EACH FAMILY

	Not well ± stress Well + stress	Well - stress	Total
One - three	66	24	90
Four or more	25	29	54
Total	91	53	144
	P = less than .01	X^2 = 9.4765	

TABLE 13 - 5 PARENTS' ASSESSMENT OF ABILITY TO COPE BY NUMBER OF CHILDREN NOW ALIVE IN EACH FAMILY

	Not well ± stress Well + stress	Well - stress	Total
One to three	44	46	90
Four or more	20	34	54
Total	64	80	144
	P = N.S.	X^2 = 1.4698	

The interviewers (Table 13 - 4) more often than the parents (Table 13 - 5) judged larger families to be coping well without stress.

TABLE 13 - 6 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY NUMBER OF CHILDREN NOW ALIVE IN EACH FAMILY

	More handicapped	Less handicapped	Not tested	Total
One - three	37	27	26	90
Four or more	17	28	9	54
Total	54	55	35	144

P = less than .05 $X^2 = 6.2517$

Taking into account the psychologist's assessment the more handicapped children tended to come from smaller families (Table 13 - 6).

TABLE 13 - 7 MOTHER'S FAMILY SIZE PLANS BY NUMBER OF CHILDREN NOW ALIVE IN EACH FAMILY

	No effect	No more children	Other	Total
One - three	48	33	9	90
Four or more	39	10	5	54
Total	87	43	14	144

P = greater than .05 $X^2 = 5.7338$

Table 13 - 7 shows that seven in ten mothers (72%) with four or more children said the presence of the handicapped child had no effect on their family size plans.

14. Unsuccessful Pregnancies	No.	Per cent.
None	98	68.1
One	36	25.0
Two (seven cases) or Three (three cases)	10	6.9

Originally this question was meant to reveal only the number of natural terminations or miscarriages, but four mothers mentioned abortions and these have been counted in the total. We did not determine in any given case whether the miscarriage occurred before or after the birth of the handicapped child. No significant trends were found on a social class analysis.

15. Ordinal Position of the Child	No.	Per cent.
Only	6	4.2
Oldest	27	18.7
Youngest	66	45.8
Middle	45	31.2

TABLE 15 - 1 SOCIAL CLASS BY ORDINAL POSITION OF CHILD

	I - II	III	IV - V	Other	Total
Oldest/Only	5	12	6	10	33
Youngest	13	28	17	8	66
Middle	6	15	15	9	45
Total	24	55	38	27	144

P = N.S. $X^2 = 6.9330$

TABLE 15 - 2 DEGREE OF MENTAL HANDICAP OF CHILD BY ORDINAL POSITION OF CHILD

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Oldest/Only	11	12	10	33
Youngest/Middle	50	47	14	111
Total	61	59	24	144

P = N.S. $X^2 = 5.8211$

TABLE 15 - 3 MOTHER'S RELATIONSHIP TO CHILD BY ORDINAL POSITION OF CHILD

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Oldest/Only	11	7	15	33
Youngest/Middle	19	28	64	111
Total	30	35	79	144

P = N.S. $X^2 = 4.0696$

In the case of social class (Table 15 - 1), degree of mental handicap (Table 15 - 2) and maternal relationship to the child (Table 15 - 3) the differences in distribution by ordinal position of the child are not significant.

16. Age of Mother at Birth of Child	No.	Per cent.
Less than 26	46	31.9
26 - 35	70	48.6
36 - 45	26	18.1
46 and over	2	1.4

Mean age: 29.84 years

17. Age of Father at Birth of Child	No.	Per cent.
Less than 26	26	18.1
26 - 35	58	40.3
36 - 45	46	31.9
46 and over	11	7.6
Not known	3	2.1

Mean age: 33.14 years

In addition to the comments already noted (see Question 5) one family did not know the age of the father of their adopted daughter.

TABLE 16 - 1 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY AGE OF MOTHER AT BIRTH OF CHILD

	More handicapped	Less handicapped	Not tested	Total
Less than 35	37	49	30	116
36 and over	17	6	5	28
Total	54	55	35	144
	P = N.S.	X^2 = 8.1468		

Table 16 - 1 shows that almost seven in ten (68.6%) mothers whose child had been assessed as more handicapped were in the less than 35 age group when the child was born.

SECTION II DATA ON THE CHILD

18. Degree of Mental Handicap	No.	Per cent.
Not handicapped	19	13.2
Not sure if handicapped	42	29.2
Some mental handicap	59	40.9
Severe mental handicap	24	16.7

When asked for the diagnosis as known to them the parents' replies are listed below (tabulated by the degree of handicap they assessed):-

Diagnosis	No/Not sure	Some	Severe	Total
Mongol	7	27	4	38
Brain damage (oxygen loss)	2	2	7	11
Spastic ± epileptic	3	3	4	10
Encephalitic virus	0	1	0	1
Microcephalus	0	0	1	1
Hydrocephalus	0	2	0	2
Meningitis	1	0	1	2
Primary amnesia	0	1	0	1
Prader-Willi syndrome	0	1	0	1
Happy puppet syndrome	0	1	0	1
Hyperactive	1	1	0	2
Dormant, vegetable	0	0	2	2
Backward, slow, borderline	27	4	0	31
Accident damage	1	1	0	2
No idea	0	15	5	20
Not handicapped at all	19	0	0	19
Total	61	59	24	144

As we did not check these diagnoses as known to the parents against the medical records, either before or after the interviews, we were advised to accept the parents' testimony on Mongolism alone as a reliable factor for separate analysis. Further data on this group (26.9%) within the total sample is collected together under Question 101.

What emerges clearly from the list of diagnoses is that parents who have a 'label' they can pin on their child's condition find this an aid to acknowledging the presence of mental handicap, whilst parents with no such 'label' tend to deny or suspend judgment on the presence of mental handicap. We recognise, however, that some parents in this latter category may have been given a 'label' which they have forgotten or denied.

TABLE 18 - 1 HANDEDNESS OF CHILD BY DEGREE OF MENTAL HANDICAP OF CHILD

	Left/Both handed	Right handed	Total
None/Not sure	17	44	61
Some handicap	30	28	58
Severe handicap	10	10	20
Total	57	82	139

Excluded are the five Cogarburn Hospital children with "no grip".

P = less than .05 $X^2 = 7.7746$

There is a significant tendency for parents of right handed children to regard them as not handicapped or as less handicapped (Table 18 - 1).

TABLE 18 - 2 SOCIAL CLASS BY DEGREE OF MENTAL HANDICAP OF CHILD

	I - II	III	IV - V	Other	Total
None/Not sure	5	24	16	16	61
Some handicap	13	25	12	9	59
Severe handicap	6	6	10	2	24
Total	24	55	38	27	144
	P = greater than .05			X^2 = 12.5468	

Parents from Classes I - II tend to estimate some degree of mental handicap in 75% of cases, whereas just under half the parents (49.2%) in Classes IV, V and Other do not consider the child as handicapped or are unsure (Table 18 - 2).

TABLE 18 - 3 MOTHER'S RELATIONSHIP TO CHILD BY DEGREE OF MENTAL HANDICAP OF CHILD

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
None/Not sure	11	14	36	61
Some handicap	8	14	37	59
Severe handicap	11	7	6	24
Total	30	35	79	144
	P = less than .01		X^2 = 13.9707	

Almost one half (45.8%) the mothers who regard the child as severely mentally handicapped exhibit a protective or exclusive attitude towards him (Table 18 - 3).

TABLE 18 - 4 MOTHER'S FAMILY SIZE PLANS BY DEGREE OF MENTAL HANDICAP OF CHILD

	No effect	No more children	Other	Total
None/Not sure	48	8	5	61
Some handicap	33	21	5	59
Severe handicap	6	14	4	24
Total	87	43	14	144

P = less than .01 X^2 = 22.8741

Similarly, 81% of mothers who say that they do not want any more children assess the child as handicapped or severely handicapped (Table 18 - 4).

TABLE 18 - 5 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY DEGREE OF MENTAL HANDICAP OF CHILD

	More handicapped	Less handicapped	Not tested	Total
None/Not sure	10	38	13	61
Some handicap	30	15	14	59
Severe handicap	14	2	8	24
Total	54	55	35	144

P = less than .01 X^2 = 31.2634

Table 18 - 5 compares the parents' assessment of the child's handicap by the psychologist's in terms of proposed educational placement. The overall differences in distribution are highly significant, but the interpretation must be qualified as no less than 35 (24.3%) of these children had not been (finally) assessed by the educational psychologist. Re-examining the table after removing this group of 35 not tested children, there are no significant differences.

TABLE 18 - 6 ORDINAL POSITION OF CHILD BY DEGREE OF MENTAL HANDICAP OF CHILD

	Oldest/Only	Youngest	Middle	Total
None/Not sure, Some handicap	23	57	40	120
Severe handicap	10	9	5	24
Total	33	66	45	144

P = greater than .05 X^2 = 5.8536

Table 18 - 6 indicates that in only one in five families (20.8%) with a middle child was he judged as severely handicapped.

19. Degree of Physical Handicap	No.	Per cent.
No physical handicap	84	58.3
Some physical handicap	40	27.8
Severe physical handicap	20	13.9

The diagnoses as known to the parents are listed below by their assessment of the degree of physical handicap:-

Diagnosis	None	Some	Severe	Total
Spastic/cerebral palsy	1	7	5	13
Epileptic	1	10	2	13
Hole-in-heart, murmur	1	7	1	9
Hemiplegia/diplegia, etc.	0	3	2	5
Blindness	0	1	3	4
Brain damage (oxygen loss)	0	1	1	2
Spina bifida	1	0	0	1
Meningocele	0	1	0	1
Poliomyelitis	0	0	1	1
Moby syndrome	0	1	0	1
Muscular weakness	0	2	0	2

Diagnosis	None	Some	Severe	Total
Not known	0	7	5	12
Not physically handicapped	80	0	0	80
Total	84	40	20	144

Four parents were confused and pained enough to give us the diagnosis of the child's physical handicap which they had been given but to deny the fact of his physical handicap. This accounts for the discrepancy between the two totals, of 80 and 84, for those 'not physically handicapped'. As before we did not check their memories or diagnoses against medical records. Comparing the check list of mental handicap and physical handicap diagnoses as known to the parents these points emerge:-

Parents of spastic children and of epileptic children denied any mental handicap in three cases, any physical handicap in two cases; admitted some/severe mental handicap in seven cases, some/severe physical handicap in twenty four cases.

Parents of brain damaged children associated the condition with mental handicap in nine cases, with physical handicap in two cases.

Of the eighty three parents admitting to some mental handicap in the child, twenty (24.1%) did not know the diagnosis; of the sixty parents admitting to some physical handicap in the child, twelve (20%) did not know the diagnosis.

Whilst many children were multiply handicapped, it does look as though the popular belief (that it is easier and less shameful to admit to physical than to mental handicap in one's child) is substantiated in the case of the parents we interviewed. Two thirds (40 out of 60) of those volunteering some diagnosis of physical handicap express

acceptance of the child's status as mentally handicapped, whereas only half (43 out of 84) reporting no physical handicap accept the presence of mental handicap. The significance of accepting a diagnosis of physical handicap as an overlay to fundamental mental handicap appears in many subsequent contexts.

TABLE 19 - 1 BIRTHWEIGHT OF CHILD BY DEGREE OF PHYSICAL HANDICAP OF CHILD

	Less than 4.15 lbs	5 - 6.15 lbs	More than 7 lbs	Not known	Total
No physical handicap	4	30	44	6	84
Some physical handicap	3	18	16	3	40
Severe physical handicap	4	10	6	0	20
Total	11	58	66	9	144

P = N.S. $\chi^2 = 9.6704$

There is some trend for low birthweight to be associated with the presence of physical handicap but this does not reach significance (Table 19 - 1).

TABLE 19 - 2 ORDINAL POSITION OF CHILD BY DEGREE OF PHYSICAL HANDICAP

	Oldest/Only	Youngest	Middle	Total
No physical handicap	16	38	30	84
Some physical handicap	9	18	13	40
Severe physical handicap	8	10	2	20
Total	33	66	45	144

P = N.S. $X^2 = 6.6325$

Again, ordinal position of the child shows a trend for middle children not to have physical handicap but the differences are not significant (Table 19 - 2).

TABLE 19 - 3 DEGREE OF MENTAL HANDICAP OF CHILD BY DEGREE OF PHYSICAL HANDICAP OF CHILD

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No physical handicap	41	39	4	84
Some physical handicap	16	17	7	40
Severe physical handicap	4	3	13	20
Total	61	59	24	144

P = less than .01 X^2 = 42.3565

Expectedly, severe mental handicap correlates in a significant manner with severe physical handicap (Table 19 - 3).

TABLE 19 - 4 MOTHER'S RELATIONSHIP TO CHILD BY DEGREE OF PHYSICAL HANDICAP OF CHILD

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No physical handicap	13	15	56	84
Some physical handicap	9	12	19	40
Severe physical handicap	8	8	4	20
Total	30	35	79	144

P = less than .01 X^2 = 15.6939

Maternal attitudes tend to be protective/exclusive in the presence of physical handicap and accepting in the absence of such handicap (Table 19 - 4).

TABLE 19 - 5 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY DEGREE OF PHYSICAL HANDICAP OF CHILD

	Not well ± stress	Well + stress	Well - stress	Total
No physical handicap	6	39	39	84
Some physical handicap	6	22	12	40
Severe physical handicap	2	16	2	20
Total	14	77	53	144

P = less than .05 X^2 = 11.6727

The interviewers' assessment of parents who coped not well or well with stress shows a significant correlation with physical handicap (Table 19 - 5). Two parents with a severely physically handicapped child who were judged to be coping well without stress had admitted their child to Cogarburn Hospital. Against that, however, another two parents with a severely physically handicapped child who were judged to be coping not well with stress had also admitted their child to Cogarburn Hospital. This would suggest that the dynamics of these marriages were affected by factors other than being the parents of a severely mentally and physically handicapped child.

20.	Degree of Mobility/Continence	No.	Per cent.
	Continent and mobile	73	50.7
	Continent, some physical limitation	8	5.6
	Incontinent but mobile	29	20.1
	Incontinent, some physical limitation	19	13.2
	Incontinent, severe physical limitation	15	10.4

TABLE 20 - 1 SOCIAL CLASS BY DEGREE OF MOBILITY/CONTINENCE OF CHILD

	I - II	III	IV - V	Other	Total
Continent ± some limitation	12	37	14	18	81
Incontinent but mobile	6	7	11	5	29
Incontinent, some/ severe limitation	6	11	13	4	34
Total	24	55	38	27	144

P = greater than .05 X^2 = 10.7171

There was some linkage between incontinence/mobility and social class; more than half (52.3%) of children in Classes IV, V and Other were incontinent (Table 20 - 1).

TABLE 20 - 2 MOTHER'S RELATIONSHIP TO CHILD BY DEGREE OF MOBILITY/CONTINENCE OF CHILD

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Continent ± some limitation	17	9	55	81
Incontinent but mobile	2	12	15	29
Incontinent, some/ severe limitation	11	14	9	34
Total	30	35	79	144

P = less than .01 X^2 = 25.6894

Maternal attitudes seemed to be correlated with incontinence. No less than 70% of mothers judged as ambivalent or rejecting had children who were incontinent (Table 20 - 2).

TABLE 20 - 3 MOTHER'S FAMILY SIZE PLANS BY DEGREE OF MOBILITY/CONTINENCE OF CHILD

	No effect	No more children	Other	Total
Continent ± some limitation	58	18	5	81
Incontinent but mobile	16	10	3	29
Incontinent, some/severe limitation	13	15	6	34
Total	87	43	14	144

P = less than .02 X^2 = 11.9409

Of the mothers who had decided to have no more children 58% had handicapped children who were incontinent (Table 20 - 3).

TABLE 20 - 4 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY DEGREE OF MOBILITY/CONTINENCE OF CHILD

	Not well ± stress	Well + stress	Well - stress	Total
Continent ± some limitation	6	33	42	81
Incontinent but mobile	5	19	5	29
Incontinent, some/severe limitation	3	25	6	34
Total	14	77	53	144

P = less than .01 X^2 = 19.3498

Table 20 - 4, interviewers' assessment of parents' coping ability by degree of mobility/continence, shows a marked correlation between incontinence and parental stress.

TABLE 20 - 5 DEGREE OF MENTAL HANDICAP OF CHILD BY DEGREE OF MOBILITY/CONTINENCE OF CHILD

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Continent ± some limitation	45	33	3	81
Incontinent but mobile	9	15	5	29
Incontinent, some/ severe limitation	7	11	16	34
Total	61	59	24	144

P = less than .01 X^2 = 36.4632

With regard to parents' assessment of degree of mental handicap, 87.5% of children assessed as severely mentally handicapped were also incontinent (Table 20 - 5).

21. Current Health of Child	No.	Per cent.
No complaints or disabilities	57	39.6
Complaints only	36	25.0
Complaints and disabilities (including the nine children in Gogarburn Hospital)	51	35.4

TABLE 21 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY CURRENT HEALTH OF CHILD

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No complaints or disabilities	32	23	2	57
Complaints only	15	20	1	36
Complaints and disabilities	14	16	21	51
Total	61	59	24	144

P = less than .01 X^2 = 36.7260

Nine in ten (93.3%) of those children adjudged by their parents to be severely mentally handicapped were also in the poorest current health (Table 21 - 1).

TABLE 21 - 2 MOTHER'S RELATIONSHIP TO CHILD BY CURRENT HEALTH OF CHILD

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No complaints or disabilities	3	13	41	57
Complaints only	9	6	21	36
Complaints and disabilities	18	16	17	51
Total	30	35	79	144

P = less than .01 X^2 = 21.4309

Maternal attitudes indicate that whereas 90% of protective/exclusive mothers ranked the child in poor health, 62.8% of ambivalent or rejecting mothers, and only 48% of accepting mothers thought their child enjoyed poor health at the time (Table 21 - 2).

TABLE 21 - 3 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY CURRENT HEALTH OF CHILD

	Not well ± stress Well + stress	Well - stress	Total
No complaints or disabilities	31	26	57
Complaints only	16	20	36
Complaints and disabilities	44	7	51
Total	91	53	144

P = less than .01 X^2 = 19.0222

Table 21 - 3 indicates that the interviewers noted the stress factor of the child's poor health; 66.6% of parents whose child was not in good health were scored as coping not well or well with stress.

TABLE 21 - 4 PARENTS' ASSESSMENT OF ABILITY TO COPE BY CURRENT HEALTH OF CHILD

	Not well ± stress Well + stress	Well - stress	Total
No complaints or disabilities	21	36	57
Complaints only	8	28	36
Complaints and disabilities	35	16	51
Total	64	80	144
	P = less than .01	X^2 = 20.9785	

The parents were equally aware of the stress imposed by a child in poor health; 67.1% of such parents feeling themselves to be coping not well or well with stress (Table 21 - 4).

As the visits themselves spread over nine months, it is remarkable how many parents had decided to keep at home a child who enjoyed poor health as well as causing so much extra work and worry.

22. Impairment of Vision	No.	Per cent.
None	107	74.3
Partial sight	16	11.1
Squint, lazy eye, etc.	15	10.4
Blind	6	4.2

23. Impairment of Hearing	No.	Per cent.
None	130	90.3
Sore/running ears	5	3.5
Partial deafness	9	6.2

One in every four children in our sample had vision problems as compared with one in every ten with hearing problems. These sight and hearing problems must profoundly limit the abilities of children already mentally handicapped. The numbers, however, are too small for further comment.

24. Age of Child when Words first used	No.	Per cent.
Less than 12 months	17	11.8
12 - 23 months	34	23.6
24 - 35 months	29	20.1
36 - 47 months	14	9.7
48 - 59 months	12	8.3
5 years and over	6	4.2
Never	17	11.8
Accident setback	8	5.6
Not known	7	4.9

Eight parents at this stage, seven with regard to phrases and sentences, maintained that their child had been speaking normally until his speech was slowed, regressed or halted altogether after an accident in the street, playground or house. We record this regardless of any suspicions that in some cases it is an example of "post hoc ergo propter hoc" reasoning. The mothers who did not know when this child had first used words either had large families and had forgotten or were generally incompetent as mothers, or at least as informants in the interview.

25. Age of Child when Phrases first used	No.	Per cent.
12 - 23 months	7	4.9
24 - 35 months	19	13.2
36 - 47 months	25	17.4
48 - 59 months	22	15.3
5 years and over	19	13.2
Never	38	26.4
Accident setback	7	4.9
Not known	7	4.9

26. Age of Child when Sentences first used	No.	Per cent.
24 - 35 months	7	4.9
36 - 47 months	10	6.9
48 - 59 months	23	15.9
5 years and over	33	22.9
Never	61	42.4
Accident setback	7	4.9
Not known	3	2.1

There seemed to be ready appreciation on the part of many parents that speech onset is a good predictor of future development. In many homes we listened to the story, "He's all right but for his speaking." We triggered off at this point in the interview a protest that culminated in the demand for more speech therapists (see Questions 86, 87 and 90). Time and again parents singled out poor speech, incoherent speech or no speech at all as the child's besetting, if not sole handicap. One mother said:-

"It's like winning a thousand pounds when he puts two words together."

It was felt unwise to place too much credence on the parents' memories of the child's month-by-month build up of speech, but we utilised a condensed version of his onset of using words as a reliable factor.

TABLE 24 - 1 HANDEDNESS OF CHILD BY AGE OF CHILD WHEN WORDS FIRST USED

	Left/Both handed	Right handed	Total
Under 3 years	31	49	80
3 - 5 years	12	14	26
5 years and Never	12	7	19
Other/Not known	2	12	14
Total	57	82	139

Excluded are the five Gogarburn Hospital children with "no grip"

P = less than .05 X^2 = 8.4385

Table 24 - 1 shows a significant trend for right handed children to use words earlier than left handed or ambidextrous children.

TABLE 24 - 2 SOCIAL CLASS BY AGE OF CHILD WHEN WORDS FIRST USED

	I - II	III	IV - V	Other	Total
Under 3 years	16	38	15	11	80
3 - 5 years	4	6	9	7	26
5 years and Never	4	8	10	1	23
Other/Not known	0	3	4	8	15
Total	24	55	38	27	144

P = less than .01 X^2 = 26.8919

Children from Classes I - II tend to use words earlier than other children (Table 24 - 2).

TABLE 24 - 3 DEGREE OF MENTAL HANDICAP OF CHILD BY AGE OF CHILD WHEN WORDS FIRST USED

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Under 3 years	35	40	5	80
3 - 5 years	11	9	6	26
5 years and Never	4	7	12	23
Other/Not known	11	3	1	15
Total	61	59	24	144

P = less than .01 X^2 = 35.0476

Similarly and expectedly, there is a correlation between severe mental handicap and late or no speech (Table 24 - 3).

27. Other Relative with slow speech start	No.	Per cent.
No	103	71.5
Yes	41	28.5

TABLE 27 - 1 SOCIAL CLASS BY OTHER RELATIVE WITH SLOW SPEECH START

	I - II	III	IV - V & Other	Total
No	16	39	48	103
Yes	8	16	17	41
Total	24	55	65	144

P = N.S. X^2 = 0.4605

Little can be made of the information yielded by this question, except to point out that there was a fairly even distribution across the social classes of families having a relative other than the handicapped child whose speech onset was late (Table 27 - 1).

28. Handedness of Child	No.	Per cent.
Left handed	33	22.9
Both handed	24	16.7
Right handed	82	56.9
No grip	5	3.5

The five children in Gogarburn Hospital were described as having no grip and could not even be classified with the ambidextrous children.

TABLE 28 - 1 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY HANDEDNESS OF CHILD

	More handicapped	Less handicapped	Not tested	Total
Left/Both handed	27	15	15	57
Right handed	22	40	20	82
Total	49	55	35	139

Excluded are the five Gogarburn Hospital children with "no grip"

P = less than .01 X^2 = 34.1392

Table 28 - 1 indicates that the majority of children (72.7%) assessed by the psychologist as less handicapped are right handed. We have already seen (Table 6 - 1) that 59% of children in Classes I - II are left handed or ambidextrous as compared with 30.6% of children from Classes IV, V and Other.

29. Child subject to Fits	No.	Per cent.
No	110	76.4
Yes in the past, but not now	12	15.3
Yes at present	22	8.3

A period of a year or more since his last seizure was the criterion for classifying a child in the second group.

TABLE 29 - 1 SEX OF CHILD BY WHETHER CHILD SUBJECT TO FITS

	Male	Female	Total
No	76	34	110
Yes in past	11	1	12
Yes at present	9	13	22
Total	96	48	144

P = less than .01 X^2 = 10.2334

Proportionately more girls (29.1%) than boys (20.4%) had been subject to fits at some time, whilst 59.9% of those currently fitting were girls (Table 29 - 1). This was the sole index on which girls outnumbered boys in the entire questionnaire.

TABLE 29 - 2 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY WHETHER CHILD SUBJECT TO FITS

	Not well ± stress Well + stress	Well - stress	Total
No	62	48	110
Yes in past	9	3	12
Yes at present	20	2	22
Total	91	53	144

P = less than .01 X^2 = 10.1906

The interviewers assessed 91% of parents whose child was currently having seizures as coping not well or well with stress (Table 29 - 2). The two families with such a child who were judged to be coping well without stress had hospitalized their child. One family who were coping well with stress had been re-housed in a ground floor flat by the Corporation; one family who were coping not well with stress were realistically troubled by the dangers of the decaying staircase in their condemned Corporation owned tenement flat.

TABLE 29 - 3 DEGREE OF MENTAL HANDICAP OF CHILD BY WHETHER CHILD SUBJECT TO FITS

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	48	51	11	110
Yes in past	4	2	6	12
Yes at present	9	6	7	22
Total	61	59	24	144

P = less than .01 X^2 = 17.7656

Over one third (40.9%) of parents whose child currently had seizures considered him not mentally handicapped or were not sure (Table 29 - 3).

TABLE 29 - 4 SOCIAL CLASS BY WHETHER CHILD SUBJECT TO FITS

	I - II	III	IV - V	Other	Total
No	18	43	29	20	110
Yes in past	5	3	2	2	12
Yes at present	1	9	7	5	22
Total	24	55	38	27	144

P = N.S. X^2 = 7.9653

The differences are not significant, but social class analysis reveals that whereas 41.6% of all children who had fitted in the past were from Classes I - II, only one child of the 22 now fitting came from these Classes (Table 29 - 4). This could be accounted for by the professional class parents more quickly and accurately identifying their child fitting, by making better use of preventive treatment or, indeed, other unknown factors.

30. Mentally Handicapped Sibling in the Family	No.	Per cent.
No	123	85.4
Yes	21	14.6

TABLE 30 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY WHETHER CHILD HAS A MENTALLY HANDICAPPED SIBLING

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	44	55	24	123
Yes	17	4	0	21
Total	61	59	24	144

P = less than .01 X^2 = 15.6245

Almost one in three children (27.8%) regarded by their parents as not being mentally handicapped have in fact a mentally handicapped sibling (Table 30 - 1).

TABLE 30 - 2 ORDINAL POSITION OF CHILD BY WHETHER CHILD HAS A MENTALLY HANDICAPPED SIBLING

	Oldest/Only	Youngest	Middle	Total
No	32	59	32	123
Yes	1	7	13	21
Total	33	66	45	144

P = less than .01 X^2 = 11.7663

Similarly, almost one in three (29%) of middle children have a mentally handicapped sibling as against less than 11% of youngest children (Table 30 - 2).

TABLE 30 - 3 MOTHER'S RELATIONSHIP TO CHILD BY WHETHER CHILD HAS A MENTALLY HANDICAPPED SIBLING

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No	28	31	64	123
Yes	2	4	15	21
Total	30	35	79	144

P = less than .05 X^2 = 6.9493

Nearly three quarters (71.4%) of the mothers with families containing two or more handicapped children were judged to be accepting in attitude, 9.5% being thought protective/exclusive and 19% ambivalent or rejecting (Table 30 - 3).

TABLE 30 - 4 MOTHER'S FAMILY SIZE PLANS BY WHETHER CHILD HAS A MENTALLY HANDICAPPED SIBLING

	No effect	No more children	Other	Total
No	71	39	13	123
Yes	16	4	1	21
Total	87	43	14	144

P = N.S. X^2 = 2.5961

Table 30 - 4 shows that three quarters (76.1%) of the mothers in question claim that the presence of two or more mentally handicapped children has had no effect on their family size plans, although the differences are not significant.

TABLE 30 - 5 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY WHETHER CHILD HAS A MENTALLY HANDICAPPED SIBLING

	More handicapped	Less handicapped	Not tested	Total
No	51	39	33	123
Yes	3	16	2	21
Total	54	55	35	144

P = less than .01 $X^2 = 15.0344$

Table 30 - 5 indicates that 76.1% of all the families having two or more handicapped children have had the index child assessed by the psychologist as less handicapped.

TABLE 30 - 6 SOCIAL CLASS BY WHETHER CHILD HAS A MENTALLY HANDICAPPED SIBLING

	I - II	III	IV - V	Other	Total
No	24	48	33	18	123
Yes	0	7	5	9	21
Total	24	55	38	27	144

P = less than .01 $X^2 = 11.9309$

Table 30 - 6 reveals that one third of the families with two or more mentally handicapped children are in Class III, the remaining two thirds in Classes IV, V and Other, and none, therefore, in Classes I - II.

This social class analysis is the last piece of the jigsaw puzzle which makes it evident that in these six tables we have been defining the subcultural end of the spectrum of mental handicap. There were two families, each with two handicapped boys and no other children, who did not fit that description, but they were the exceptions that helped to prove the rule.

31. Psychologically Ill Sibling	No.	Per cent.
No	141	97.9
Yes	3	2.1

The three children who qualified for the category of psychologically ill (following advice from the medical supervisor) were:- a girl described by her mother as "a potential neurotic" (the interviewers noted the almost total deprivation this girl suffered due to her mother's total commitment to her profoundly mentally and physically handicapped twin sister); a boy who imitated the panic behaviour pattern which his mother used to manifest when the index boy suffered seizures (the more remarkable in that his imitative behaviour was still practised well over a year since his brother last fitted); a boy who had benign muscular dystrophy was highly intelligent and knew both what was wrong with him and his spastic and retarded brother, was described by his mother as "highly strung."

32. Physically Ill Sibling	No.	Per cent.
No	122	84.7
Yes	22	15.3

As far as we could determine no significant information was yielded by these two questions.

33. Age of Child when Parents told of his Handicap	No.	Per cent.
Less than 12 months	70	48.6
12 - 23 months	12	8.3
24 - 35 months	11	7.6
36 - 47 months	4	2.8
49 - 59 months	10	6.9
5 years and over (5 allegedly Never)	37	25.7

As all the parents we interviewed had given their permission for the projected interview to medical or educational personnel already in contact with the families as families with a mentally handicapped child, it was technically impossible for any parents to claim that they had never been told of their child's handicap. However, five parents found it necessary to admit ignorance, launch into a tirade against the non-informants and express surprise at the news we, the interviewers, brought into the home.

TABLE 33 - 1 SOCIAL CLASS BY AGE OF CHILD WHEN PARENTS TOLD OF HANDICAP

	I - II	III	IV - V & Other	Total
Up to 3 years	18	39	36	93
Later or never	6	16	29	51
Total	24	55	65	144

P = less than .02 X^2 = 8.8342

Table 33 - 1 indicates that 75% of parents in Classes I - II had been told of the child's handicap by the age of 3 years, whilst this was true of only 55% of parents in Classes IV, V and Other.

TABLE 33 - 2 MOTHER'S FAMILY SIZE PLANS BY AGE OF CHILD WHEN PARENTS TOLD OF HANDICAP

	No effect	No more children	Other	Total
Up to 3 years	46	36	11	93
Later or never	41	7	3	51
Total	87	43	14	144

P = less than .01 X^2 = 13.2975

The fact of later telling (i.e. after the child was 3 years old) had had no effect on the family size plans of 80% of such mothers (Table 33 - 2).

TABLE 33 - 3 MOTHER'S RELATIONSHIP TO CHILD BY AGE OF CHILD WHEN TOLD OF HANDICAP

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Up to 3 years	29	26	38	93
Later or never	1	9	41	51
Total	30	35	79	144

P = less than .01 X^2 = 24.3226

The majority of mothers who were told later (80.3%) were judged to be accepting in attitude towards the child (Table 33 - 3).

TABLE 33 - 4 ORDINAL POSITION OF CHILD BY AGE OF CHILD WHEN TOLD OF HANDICAP

	Oldest/Only	Youngest	Middle	Total
Up to 3 years	28	47	18	93
Later or never	5	19	27	51
Total	33	66	45	144

P = less than .01 X^2 = 19.0815

Almost two thirds (62%) of parents whose handicapped child was a middle child had in fact been told later of his handicap (Table 33 -4).

TABLE 33 - 5 DEGREE OF MENTAL HANDICAP OF CHILD BY AGE OF CHILD WHEN TOLD OF HANDICAP

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Up to 3 years	25	45	23	93
Later or never	36	14	1	51
Total	61	59	24	144

P = less than .01 X^2 = 28.6228

In the case of 96% of children regarded by their parents as severely mentally handicapped the parents had been told before the child was 3 years old (Table 33 - 5). In fact, all 24 parents in this category had been told by the time the child was 3 years old; the only family to deny this revealed in other verbatims their indignation at the manner of telling within the first year of the child's life.

34. Parents' Prior Knowledge of Child's Handicap	No.	Per cent.
No	68	47.2
Yes	76	52.8

Just over half the parents claimed to have suspected or known of the child's handicap before they were told of it.

TABLE 34 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY PARENTS' PRIOR KNOWLEDGE OF CHILD'S HANDICAP

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	32	26	10	68
Yes	29	33	14	76
Total	61	59	24	144

P = N.S. X^2 = 0.9889

Almost half the parents (48.8%) who think that their child is not handicapped or are not sure claim that they knew before they were told, a paradox evident in Table 3 - 1. It echoes the ambivalence recorded in answer to the question, "In comparison with other children do you think A is handicapped?" Many of the parents claiming at this point (Question 34) to know he was handicapped before being told, had hesitated earlier (Question 18) to call him handicapped. They saw that he would be slow like (some of) his brothers and sisters and, like them, would probably go to Special School, but that was no more evidence of his mental handicap than of theirs.

35. Age of Child when Parents knew of his Handicap	No.	Per cent.
Less than 12 months	49	34.0
12 - 23 months	7	4.9
24 - 35 months	9	6.2
36 - 47 months	2	1.4
48 - 59 months	9	6.2
5 years and over	5	3.5
Not applicable (parents did not know beforehand)	63	43.7

Without checking their memories against official records of when the diagnostic interview took place, we list overleaf the gap between parents knowing and being told of their child's handicap.

Year parents were told

		1st	2nd	3rd	4th	5th	6th	Never	Total
	1st	19	0	1	1	1	0	0	22
	2nd	1	1	0	1	1	1	0	5
Year	3rd	0	0	3	0	0	3	0	6
parents	4th	0	0	0	0	0	0	1	1
knew	5th	0	0	0	0	2	1	0	3
	6th	0	0	0	0	0	2	0	2
	Never	1	1	0	0	0	3	3	8
	Total	21	2	4	2	4	10	4	47

Some discrepancies have occurred between the 63 Not applicables of Question 35 and the 68 No's of Question 34, and we cannot identify the five in question with the five who claim never to have been told in answer to Question 33. There was, in fact, so much parental hesitation and contradiction at this point, as if they sensed we were about to enter into an area of painful memories for them, that the number of inconsistencies is remarkably small.

The table as it stands, however, makes it plain that very few families complained of a substantial time lapse between knowing and being told but those five families who did were told in the sixth+ year and reckoned the gap since they had known to be four years in one case, three years in three cases, and one year in the last case.

The gap between knowing and being told, then, was mainly a matter of days, weeks or months rather than years. Mothers whose babies were visibly handicapped or separated from them for immediate treatment or tests; mothers who had been or who had relatives who were nurses; mothers who sensed that their husbands had been told something and urged to keep it from them until they were stronger in body and mind;

mothers who could compare this child's 'milestones' with those of his siblings - these comprised the great majority of those who knew before they were told. Verbatims about the grievances with regard to timing deficiencies in the diagnostic interview appear under Question 40.

36. Obviousness of Child's Handicap	No.	Per cent.
No	69	47.9
Yes	75	52.1

Strangely, in view of the parental denial we had already experienced, this issue of visible stigma proved the point of breakthrough in many homes. Parents volunteered information about the child's walking, talking, mannerisms, etc. which made his handicap apparent to others.

TABLE 36 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY OBVIOUSNESS OF CHILD'S HANDICAP (APPEARANCE/BEHAVIOUR)

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	43	18	8	69
Yes	18	41	16	75
Total	61	59	24	144

P = less than .01 X^2 = 21.6653

Just under one third (29.4%) of parents who said their child was not handicapped or were not sure admitted that he manifested some obvious handicapping characteristics in appearance or behaviour (Table 36 - 1).

TABLE 36 - 2 MOTHER'S RELATIONSHIP TO CHILD BY OBVIOUSNESS OF CHILD'S HANDICAP (APPEARANCE/BEHAVIOUR)

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No	14	13	42	69
Yes	16	22	37	75
Total	30	35	79	144

P = N.S. $X^2 = 2.5179$

The differences are not significant, but stigma, or perhaps the awareness of how others reacted to visible deviance in one's child, was admitted by 53.3% of protective mothers and 61.9% of ambivalent mothers (Table 36 - 2).

37. Person/Agency who told of Child's Handicap	No.	Per cent.
Hospital Doctor	92	63.9
Family Doctor	12	8.3
Nurse (4) Health Visitor (1)	5	3.5
Psychologist	32	22.2
Teacher	3	2.1

By a careful re-reading of the questionnaires we have allocated all five families who claim never to have been told (Question 33) to the group who had been told by a hospital doctor.

TABLE 37 - 1 AGE OF CHILD BY PERSON/AGENCY WHO TOLD PARENTS

	6 and over	4 - 5 years	Less than 4	Total
Doctor	64	31	9	104
Psychologist/ Teacher	35	0	0	35
Health Visitor/ District Nurse	1	4	0	5
Total	100	35	9	144

P = less than .01 $X^2 = 27.0467$

For a child under the age of 5 a doctor told the parents in all but four cases, and these families learnt from a nurse or health visitor (Table 37 - 1).

TABLE 37 - 2 SOCIAL CLASS BY PERSON/AGENCY WHO TOLD PARENTS

	I - II	III	IV - V	Other	Total
Doctor	21	41	29	13	104
Psychologist/ Teacher	3	11	8	13	35
Health Visitor/ District Nurse	0	3	1	1	5
Total	24	55	38	27	144

P = greater than .05 X^2 = 12.8840

When social class factors are considered 85% of Classes I - II families were told be a doctor, but the same trend holds to a lesser extent in other Classes (Table 37 - 2).

TABLE 37 - 3 ORDINAL POSITION OF CHILD BY PERSON/AGENCY WHO TOLD PARENTS

	Oldest/Only	Youngest	Middle	Total
Doctor	29	52	23	104
Psychologist/ Teacher	3	11	21	35
Health Visitor/ District Nurse	1	3	1	5
Total	33	66	45	144

P = less than .01 X^2 = 18.7152

In nearly half the families (48.8%) with a handicapped middle child the parents were told by the psychologist or teacher (Table 37 - 3).

TABLE 37 - 4 DEGREE OF MENTAL HANDICAP OF CHILD BY PERSON/AGENCY WHO TOLD PARENTS

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Doctor	34	50	20	104
Psychologist/ Teacher	27	7	1	35
Health Visitor/ District Nurse	0	2	3	5
Total	61	59	24	144

P = less than .01 $X^2 = 29.4965$

There was a high correlation between the degree of mental handicap as parents assessed it and who told the parents; 83.3% of parents of severely handicapped children learnt from a doctor (Table 37 - 4).

38. Place where Parents were told of Child's Handicap	No.	Per cent.
Hospital	92	63.9
Home	18	16.5
Clinic (usually Child Guidance Clinic, occasionally Maternity Clinic)	14	9.7
School	20	13.9

Those parents told at home were told in 12 cases by their G.P., in five cases by a health visitor and in one case by a teacher.

39. Satisfactory Interview when told of His Handicap	No.	Per cent.
No	76	52.8
Yes	68	47.2

TABLE 39 - 1 SOCIAL CLASS BY SATISFACTORY DIAGNOSTIC INTERVIEW

	I - II	III	IV - V	Other	Total
No	15	30	23	8	76
Yes	9	25	15	19	68
Total	24	55	38	27	144

P = greater than .05 $X^2 = 7.6988$

Over 60% of parents in Classes I - II remembered the interview as unsatisfactory, but the differences do not reach significant levels (Table 39 - 1).

TABLE 39 - 2 HANDEDNESS OF CHILD BY SATISFACTORY DIAGNOSTIC INTERVIEW

	Left/Both handed	Right handed	Total
No	35	38	73
Yes	22	44	66
Total	57	82	139

Excluded are the five Gogarburn Hospital children with "no grip"

P = less than .01 $X^2 = 11.6363$

Of the parents whose children were right handed more than half (53.6%) recalled the diagnostic interview as satisfactory, whereas 65% of the parents with left handed or ambidextrous children had memories of unsatisfactory interviews (Table 39 - 2).

By anticipating the specific complaints registered under Questions 40 - 42 we can record that 46 out of 76 (70.9%) dissatisfied families were disgruntled on two or more counts. The Hawthorn effect might have been at work here, in that the more grounds for complaint we offered the more complaints we would evoke. Parents were noticeably forthcoming in their feeling responses to this part of the interview.

Notwithstanding this caution, it could be that the doubly dissatisfied parents are the group from whom most lessons can be learned.

TABLE 39 - 3 DEGREE OF PHYSICAL HANDICAP OF CHILD BY PARENTS DOUBLY DISSATISFIED WITH DIAGNOSTIC INTERVIEW

	No physical handicap	Some physical handicap	Severe physical handicap	Total
Doubly dissatisfied	12	24	10	46
Not applicable	72	16	10	98
Total	84	40	20	144

P = less than .01 X^2 = 29.5297

Analysed by the presence of some or severe physical handicap in their child, 56.3% of the parents were doubly dissatisfied (Table 39 - 3).

TABLE 39 - 4 ORDINAL POSITION OF CHILD BY PARENTS DOUBLY DISSATISFIED WITH DIAGNOSTIC INTERVIEW

	Oldest	Only	Youngest	Middle	Total
Doubly dissatisfied	9	5	22	10	46
Not applicable	18	1	44	35	98
Total	27	6	66	45	144

P = less than .05 X^2 = 9.3268

Accepting that the number in question is small, nonetheless when the handicapped child is an only child five out of six parents were doubly dissatisfied (Table 39 - 4).

TABLE 39 - 5 HANDICAPPED CHILD IS MONGOL BY PARENTS DOUBLY DISSATISFIED WITH DIAGNOSTIC INTERVIEW

	Mongol	All others	Total
Doubly dissatisfied	24	22	46
Not applicable	14	84	98
Total	38	106	144

P = less than .01 X^2 = 23.1348

Table 39 - 5 reveals that 63.1% of parents with Mongol children were doubly dissatisfied, and that this group comprise 52.1% of the total of dissatisfied parents.

The parents of multiply handicapped children, of only children and of Mongol children constitute a vulnerable group of parents within the population of parents with mentally handicapped children. This cannot be an original finding but it could alert the medical profession to the need in these cases for extra sympathy, patience and readiness for parental projection. Doubly dissatisfied parents, moreover, account for over half the parents (62.5%) who claim they are not coping well; half the parents whose child has been psychologically assessed as more handicapped; just under half of those (44.4%) whose child is incontinent and physically limited in mobility; almost half of those (48.4%) whose child is currently in a Junior Occupation Centre (Almost certainly this group overlaps with parents of Mongols); just over half the mothers who initially (54.8%) and presently (55.5%) react to the fact of their child's handicap by blaming someone. Enough has been said to underline the crucial importance of the diagnostic interview. The inter-relationship between attitudes, experiences and needs begins with this traumatic incident when the parents learn the fact and implications of having a handicapped child.

40. Deficiency in Manner and Timing of Interview	No.	Per cent.
Unsympathetic	21	14.6
Too late	19	13.2
Too early	6	4.2
Manner and Timing unsatisfactory	9	6.2
Parents told satisfactorily on this count	89	61.8

Insofar as parents who were told satisfactorily merely commented, "Yes", or "They were kind and helpful", or "He did the best he could" the verbatims which follow necessarily reflect the sense of grievance felt by the dissatisfied parents.

N.B. Throughout the verbatims, M = mother, F = father speaking.

Examples of lack of sympathy include:-

"M: He was my first child. I was only 21. I knew nothing of mental handicap. The young doctor said to me, 'Well, you won't know then that your child is mentally handicapped', as if it were 'Hello and Goodbye'. Then he asked me whether I would like to put him in a hospital."

"M: There's no way of telling it kindly, but it was so abrupt. They kept asking me, 'What do you think is wrong with her?' Then the doctor told me, 'She's Mongol.' F: I asked, 'Is it physical or mental?' The doctor said, 'Oh, mental, of course.'"

"F: He started ordinary school and we thought he shouldn't have. The headmaster sent for us and said, 'You know your child is mentally retarded and shouldn't be at school at all.' This was the first we knew of it. He was very blunt."

Details about timing delays have appeared under Question 35, but these comments show how parents felt about the matter:-

"M: The doctors at the hospital should have told me there and then. My parents were told he only had 24 hours to live. Waiting seven months was an awful long time."

"F: I would rather know than not know. M: He was sitting there trying to appear bright when he was feeling miserable. F: It varies from case to case, and so does which one should be told first. M: It's better to be told together or the father first; never the mother first."

"F: She wasn't long enough in proper school. She needed a longer stay to prove herself."

"M: We thought blindness was the major handicap. Then to learn later it was mental retardation and physical handicap ... it was like a monster. At 10 months he was like this and would be like it at 5 years."

Seven of the nine parents who complained of both manner and timing of the unsatisfactory diagnostic interview had Mongol children. We suggest that some of the trouble may lie in the fact that doctors are able to diagnose Mongolism routinely, which leads to a matter-of-fact approach on their part, forgetting that what is commonplace to them is novel and numbing to the parents.

41. Deficiency in Content of Interview	No.	Per cent.
Too technical	3	2.1
Wrong/conflicting information	9	6.2
Too little information	35	24.3
Parents told satisfactorily on this count	97	67.4

We conflated the first two rows in our analyses but could not show any significant differences in distribution. Examples of parents who

complained that the information was too technical, or was proved wrong as events turned out included these:-

"M: First she was classified as spina bifida, now she's classified as spastic."

"F: The doctor was embarassed. 'We don't know if he'll walk or talk. As he gets older your other children will get embarassed and you'll have to put him in a home. Other people will be upset and avoid him.' That was all wrong. A health visitor put us in touch with X Hospital, and Dr. Y came every six months and gave him thyroid tablets. It seemed to help. At least someone was doing something for S. It may have been auto-suggestion. The rest all said, 'It's not my problem, it's yours; you keep it.'"

"M: I was told he only had a 50-50 chance of living, that he wouldn't cut his teeth until 18 months (he did at one year), he wouldn't put his feet under him until two years (he did at 15 months) and he wouldn't walk until eight years (he did at five years)."

Among those complaining of too little information were these parents:-

"F: The doctors don't know enough themselves. Personally, I think we're in the Dark Ages regarding mental handicap."

"F: Our only knowledge of a Mongol was of a bad one down the street. We could only dread the worst. We should have learnt that the handicap could come in different degrees. Hers is only very slight."

"M: I got a book from a library and learned most from there. It was good, answered some questions, put me at ease. Still nobody has told me anything."

42. Deficiency in Understandability of Interview	No.	Per cent.
Message not understood	5	3.5
Message understood but outlook unclear	31	21.5
Parents told satisfactorily on this count	108	75.0

In the small first category two mothers' comments were:-

"M: I can't remember how they told me. I didn't understand it until I was out of the hospital and took him to the spina bifida clinic."

"M: Some bits I didnae pick up. You ken what doctors are like for rattling on!"

Those who understood, up to a point, but were unsure of the future outlook are represented by these verbatims:-

"M: A hazy notion. No idea what it really involved. I thought he would be a monster."

"F: Nobody ever said, 'We have carefully considered your child and he is mentally handicapped.' It came out in the midstream of other information. We knew by the summer we had to tell our relatives they needn't expect A to grow up and be normal."

"F: We knew he would be handicapped, but not how badly handicapped."

Bearing in mind that the mean age of the children was 6 years 4 months the longevity and poignancy of the parents' memories is remarkable. We can only hazard the guess that their memories are equally accurate.

SECTION III DATA ON PARENTS' REACTIONS AND PAST EXPERIENCES

43. Father's Initial Reaction	No.	Per cent.
Accepted as challenge	6	4.2
Accepted with resignation	57	39.6
Denied	21	14.6
Denied and sought other opinion	2	1.4
Blamed self	5	3.5
Blamed others	15	10.4
Not known	38	26.4

44. Mother's Initial Reaction	No.	Per cent.
Accepted as challenge	9	6.2
Accepted with resignation	75	52.1
Denied	23	15.9
Denied and sought other opinion	6	4.2
Blamed self	5	3.5
Blamed others	26	18.1

45. Father's Present Reaction	No.	Per cent.
Accepts as challenge	28	19.4
Accepts with resignation	60	41.7
Denies	9	6.2
Blames others	9	6.2
Not known	38	26.4

46. Mother's Present Reaction	No.	Per cent.
Accepts as challenge	44	30.6
Accepts with resignation	80	55.6
Denies	11	7.6
Blames others	9	6.2

To demonstrate our criteria for allotting reactions to the news of the child's handicap to the various categories we will quote a selection of the verbatims, listing the initial and present reactions of the same person, noting in parentheses the interviewers' assessment of that person's relationship to the child.

Father accepted as challenge, accepts as challenge:-

"'Well, what do you think, love? I think we'll take her home.' There was no argument.... You couldn't wish for a more loving child (Accepting)."

"When the psychologist told me it meant smaller classes, more attention and that the teacher can help her most there, I said, 'If it's going to help her I'm all for it.' .... We're both pleased with her progress up till now (Accepting)."

Father accepted as challenge, accepts with resignation:-

"I think the Lord's given us three healthy ones; it's our turn for having an unhealthy one.... Small bit of bitterness. He's either kept at home or farmed out. If he's at home he's a wedge between the married couple. We have no life of our own and never will have again. The child will never grow or the burden get lighter (Ambivalent)."

Father accepted with resignation, accepts as challenge:-

"I took it very bad at first for an hour or so. Your first son you know.. but then you realise this is life.... I still believe in miracles. I hope to see him run onto a football park some day. If a Mongol wrote a book (The Diary of Nigel Hunt) why can't one play football? I'd never change him for anything (Accepting)."

Father accepted with resignation, accepts with resignation:-

"I was terribly upset when I heard.... You've grown to know she is mentally handicapped, but at the same time you would like her to be normal. You can't talk with her. She doesn't play - she watches or stays in the background (Protective)."

Father denied, denies:-

"Disbelief. She was just slow and would catch up.... Still feel the same. I hope she'll catch up by the age of 11 or 12 (Accepting)."

Father denied, accepts as challenge or with resignation:-

"I felt like I'd murder her myself.... Now she's my blue-eyed girl (Protective)."

"Nausea. Defeated hope every morning. You don't like it but you accept it .... Now we hope the education authorities will help her and help us (Accepting)."

"At first I couldnae grasp it, believe it. It took me a long time but finally I conceded to it - after two years .... I accept it but I don't like going to Gogarburn Hospital to see him. I don't know why. When I do go there I go out and get blind drunk that night (Ambivalent)."

Father blamed self, accepts:-

"We were that fond of the bairn it didn't matter too much. I wondered if God was punishing us for something. Everything's for a purpose.... We wouldn't part with him. He loves his coffee and TV (Protective)."

Father blamed others, blames others:-

"I'm annoyed at the driver of the car which knocked him down. He was a drunk diabetic.... I'm annoyed at the school for not doing enough for C. His younger brother is outstripping him, getting more stimulation (Accepting)."

Father blamed others, accepts as challenge or with resignation:-

"I went away and wept in my laboratory. A pity for him and a fright for the future. Between my wife and I there's a balance; when one is down the other is up. He might die ... we kept on being told he wouldn't live. He was vigorously resuscitated in the hospital. The oxygen drip should have been withdrawn. I'm bitter at the paediatrician. Suddenly told he would come home. We felt remorse because we thought it would be better if he died..... He's a millstone around our neck - a trauma for ever; especially for my daughter, even if he is hospitalised. I feel immeasurably sad that he is handicapped and not a normal boy. I miss a normal boy. The frustration has built up (Ambivalent)."

Father blamed others, denies:-

"I'm bitter about the medical profession. Our next door neighbour's doctor arrived before ours did. We nearly lost her. I resent them speaking professionally to me. I'm a layman and they need to explain things in a way you can understand. It's silly pride, but you don't like to think there's anything wrong with your kid. I resented it at first. But then you realise it's her welfare, not your feelings, that matter.... I don't see any difference in her. She has a temperament and I'm pleased she's not a vegetable. She knows she's had a telling. It's there, but can't come out (Ambivalent)."

Mother accepted as challenge, accepts as challenge:-

"He fitted on the third day but wasn't discharged until three months. The doctor phoned me and said he might be epileptic, spastic or retarded, he couldn't tell which. I kept asking and asking, finally they thought he had less than a 50-50 chance of surviving. From then on I didn't care what he'd be like. I just wanted to have him for a while. It was a relief when somebody diagnosed him as a spastic. It was a challenge to look after him .... He's a delightful wee soul, a lovely wee personality. I really feel that however long we have him it's a privilege. We're not the same people we were. We've discovered new depths in ourselves (Protective)."

Mother accepted with resignation, accepts as challenge:-

"Completely shattered. It was like a death in reverse. I cried for a fortnight. I dreamt of disaster, and recognised it was so. I was terribly disappointed but refused to avoid people.... I would rather have heard all my other children had been killed. Anything he does is like a bonus. He's quite a character, with a sense of fun. In the Highlands they're called 'God's chosen' (Accepting)."

"The first two months were the worse. Once you've faced up to it you're O.K.... Each new step is a miracle. Last year he couldnae crawl, this year he can. Next year there's no knowing what may happen (Protective)."

Mother accepted with resignation, accepts with resignation:-

"I was a wee bit upset at first. I went to that Special School myself. ... I was a wee bit backward at his age (Accepting)."

"Horrified. Glad of six months ignorance.... Sad for her sake (Ambivalent)."

Mother accepted with resignation, blames others:-

"Too upset to remember. Now I'm glad he came through it.... We could help him more if the school would help us know how (Ambivalent)."

Mother denied, denies:-

"Both his sisters are at that school. He's just quiet and shy .... He's come out since he's been at the Special School. He's more boyish, wilder (Accepting)."

Mother denied, accepts as challenge or with resignation:-

"Very heartbroken. I wouldn't accept it at first, thought they were mistaken. Bitter because it had happened to me.... He's just part of the family now. There's nothing he or we can do about it (Protective)."

"I was shattered, stunned. If she had been Mongoloid you could have seen it from the beginning.... It took me until C was at Special School to really accept it. I hoped I would wake up one morning and find her normal. Now I accept it, for her sake as well as mine (Accepting)."

Mother blamed self, accepts as challenge or with resignation:-

"Couldn't understand it. Why happen to me? Why mine? Is it something I did? I made a bargain with God, 'You make him better and I'll believe.' .... Was it due to my diabetes? If you have diabetes, I've been told, it's better to lose your first child (Protective)."

Mother blamed self, denies:-

"I was very upset. What a shame. Was I wrong during my pregnancy? How did he go like that?.... I'm more worried now than I was at first. I didn't like getting an appointment card for a psychiatric clinic. He's blind, not mentally handicapped (Accepting)."

Mother blamed others, blames others:-

"I felt the world had come to an end. I think they should do something to them when they're born - especially when the doctors know.... I still feel like that. I wish something had happened to him when he was born (Ambivalent)."

"I was sorry for my husband, having had a handicapped child by another wife. I didn't go under then and I never will now .... My one worry is what happens to him when I'm not here. He can't marry and know what life is about. The injustice of it all is what gets me. I have a deep concern as to what will happen to him. I've often thought, 'Why haven't I the courage to come in and kill him?' There's nothing in him to fight for, whereas his brother (with benign muscular dystrophy) is so bright. The world is over-populated, there's abortion on demand.. why struggle to save him at the risk of our marriage and the other two children? (Ambivalent)."

Mother blamed others, accepts as challenge or with resignation:-

"I was in a terrible state, really annoyed at the beginning. She was slow, but they never gave her a chance.... The older two had four years at ordinary school before they were transferred to a special school (Accepting)."

TABLE 44 - 1 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY MOTHER'S INITIAL REACTION

	Not well ± stress	Well + stress	Well - stress	Total
Accepted	7	37	40	84
Denied	3	20	6	29
Blamed	4	20	7	31
Total	14	77	53	144

P = less than .05 X^2 = 10.3242

The interviewers assessed as coping not well or well with stress 80% of mothers who initially reacted with denial or blame (Table 44 - 1).

47. Father's Relationship to Child	No.	Per cent.
Protective	20	13.9
Exclusive	4	2.8
Ambivalent	15	10.4
Rejecting	9	6.2
Withdrawn	4	2.8
Accepting	54	37.5
Not known	38	26.4

48. Mother's Relationship to Child	No.	Per cent.
Protective	25	17.4
Exclusive	5	3.5
Ambivalent	25	17.4
Rejecting	8	5.6
Withdrawn	2	1.4
Accepting	79	54.9

The interviewers based their assessment on the strength of the verbatims noted, behaviour observed and atmosphere absorbed up to this point in the interview. Such factors influenced our decision as how often and with what feeling the parents referred to, addressed, looked at and handled the handicapped child; how, if at all, these responses differed from their dealings with his siblings; the gestures, mannerisms and rapport exhibited by the parents, and so on. The rule-of-thumb guide lines were that protective indicated a desire to protect the child at all costs; exclusive suggested an awareness on our part that the siblings were being neglected; ambivalent parents

displayed a mixture of warm and cool feelings towards and about the child; rejecting attitudes and withdrawn distancing from the child evidenced very little emotional interest, and accepting relationships suggested real warmth and understanding. In this last connection, the interviewers increasingly scored as accepting parents who were more neutral than positive, many such parents coming in the category of those who denied his handicap, expressed no criticisms of the services, foresaw no problems in the future, experienced little trauma in the present, and so on.

Lacking data on one quarter of the fathers we judged this factor as usable in a very limited connection, whereas the 'fit' between our assessment of the mother's relationship and other more objective factors encouraged us to use that factor in analysing against all other columns.

TABLE 47 - 1 MOTHER'S RELATIONSHIP TO CHILD BY FATHER'S RELATIONSHIP TO CHILD

		Mother			
		Protective Exclusive	Ambivalent, Rejecting Withdrawn	Accepting	Total
Father	Protective, Exclusive	9	5	10	24
	Ambivalent, Rejecting, Withdrawn	7	17	4	28
	Accepting	5	9	40	54
	Not known	9	4	25	38
	Total	30	35	79	144

P = less than .01 $X^2 = 40.3333$

Re-examining this table without the 38 Not known

P = less than .01 $X^2 = 33.6517$

Table 47 - 1 demonstrates the high correlation between mother's and father's relationships to the child in the majority of families. In the 106 families in which the interviewers could make judgments about both parents there were three more fathers than mothers who were protective/exclusive towards the child, and three more mothers than fathers who were ambivalent/rejecting/withdrawn towards the child.

TABLE 47 - 2 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY FATHER'S RELATIONSHIP TO CHILD

	Not well, Well + stress	Well - stress	Total
Protective, Exclusive	15	9	24
Ambivalent, Rejecting, Withdrawn	23	5	28
Accepting	29	25	54
Not known	24	14	38
Total	91	53	144

P = less than .01 X^2 = 14.8283

Fathers displaying 'negative' characteristics (i.e. all except accepting) come predominantly in the group who are coping not well or well with stress (Table 47 - 2).

TABLE 48 - 1 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY MOTHER'S RELATIONSHIP TO CHILD

	Not well ± stress	Well + stress	Well - stress	Total
Protective, Exclusive	3	18	9	30
Ambivalent, Rejecting, Withdrawn	8	23	4	35
Accepting	3	36	40	79
Total	14	77	53	144

P = less than .01 X^2 = 21.8134

The proportion of mothers with 'negative' characteristics who are judged by the interviewers to be coping not well or well with stress is 80% (Table 48 - 1).

TABLE 48 - 2 ORDINAL POSITION OF CHILD BY MOTHER'S RELATIONSHIP TO CHILD

	Oldest/Only	Youngest	Middle	Total
Protective, Exclusive	11	15	4	30
Ambivalent, Rejecting, Withdrawn	7	20	8	35
Accepting	15	31	33	79
Total	33	66	45	144

P = less than .05 X^2 = 11.6457

Half the mothers of oldest/only children and over half the mothers of youngest children were judged by the interviewers to be showing 'negative' characteristics towards the child (Table 48 - 2).

TABLE 48 - 3 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY MOTHER'S RELATIONSHIP TO CHILD

	More handicapped	Less handicapped	Not tested	Total
Protective, Exclusive	12	7	11	30
Ambivalent, Rejecting, Withdrawn	15	9	11	35
Accepting	27	39	13	79
Total	54	55	35	144

P = less than .05 X^2 = 10.9133

Exactly half the mothers of children who had been assessed as more handicapped displayed 'negative' characteristics towards the child, whilst only 29% of the mothers with less handicapped children were thought by the interviewers to show such characteristics (Table 48 - 3).

TABLE 48 - 4 DEGREE OF MENTAL HANDICAP OF CHILD BY MOTHER'S RELATIONSHIP TO CHILD

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Protective, Exclusive	11	8	11	30
Ambivalent, Rejecting, Withdrawn	14	14	7	35
Accepting	36	37	6	79
Total	61	59	24	144

P = less than .01 X^2 = 13.9707

Three quarters of the mothers who assess their child as severely handicapped exhibited 'negative' characteristics towards him (Table 48 - 4).

49. Relationship of Father's Close Relatives to Child	No.	Per cent.
Protective (6) Exclusive (2)	8	5.6
Ambivalent (2) Rejecting (8) Withdrawn (7)	17	11.8
Accepting	78	54.2
Not known	41	28.5

50. Relationship of Mother's Close Relatives to Child	No.	Per cent.
Protective (15) Exclusive (14)	29	20.1
Ambivalent (10) Rejecting (4)	14	9.7
Accepting	91	63.2
Not known	10	6.9

Our hope, to discover the importance and value to the family of their extended family network, proved forlorn. Many parents claimed that they didn't see much of their relatives, and that when they did see them most relatives did not treat the handicapped child any differently to his siblings. No useful information emerged from these questions.

51. Other Relative resident in the House	No.	Per cent.
No	131	91.7
Yes	13	9.1

Nine of the thirteen families were providing a home for an aged parent, four housed a brother or sister of one of the spouses.

TABLE 51 - 1 SOCIAL CLASS BY WHETHER RELATIVE RESIDENT IN HOUSE

	I - II	III	IV - V & Other	Total
No	22	53	56	131
Yes	2	2	9	13
Total	24	55	65	144

P = N.S. $\chi^2 = 5.0238$

Table 51 - 1 analyses by social class those families with a resident relative; 69% of these families were in Classes IV, V and Other, lived without exception in Corporation housing and were mostly families already overcrowded in their houses.

52. Effect of Child on Siblings	No.	Per cent.
No effect	52	36.1
Good effect on one	12	8.3
Good effect on all	23	15.9
Bad effect on one	29	20.1
Bad effect on all	19	13.2
Not applicable	9	6.2

In the 'Not applicable' category were six families with an only child and three families whose child was in Gogarburn Hospital. We scored in the 'Bad effect' category six children whose parents reported on the bad effect this child had had on his siblings prior to admission to Gogarburn Hospital.

Here are a few comments representing parents who claim the handicapped child has a good effect on his siblings:-

"M adores him. And A is wonderful. She says to her friends, 'This is D, my brother. He can't talk very well, but just ask me and I'll tell you what he's saying.'"

"It's had a good effect overall. R was spoiled for five years. She's accepted it and has a good relationship with A and all other small children."

"His three sisters spoil him, love playing with him. He loves plenty of attention. We took them on a week's holiday without D hoping the girls might feel free. In fact they cried and missed him terribly."

"They tend to pamper her more than they should."

"The youngest has learnt from P being on the Doman Delacato programme. He's been fiercely stimulated. He is self-sufficient. The oldest fully understands. The oldest girl helps with the physical side of the daily programme P is on."

In their own words, these parents represent the families in which the handicapped child is reckoned to have a bad effect on his siblings:-

"Whilst T was at home (he is not in Gogarburn Hospital) H was neglected. If he were at home now, she would be retarded."

"If S takes ill again it might frighten C. S is very demanding on me and C gets excluded."

"S cries a lot. But she helps me wheel F around."

"Restricting. D wants to be in amongst them and their friends and hobbies. All the children have their own room which they can lock. When D was away for five days at Humbie Village we breathed again and saw how free our children could be."

"B is upset by other children taking advantage of S, calling him 'mental'. S is aggressive and that puts a strain on her. I feel sorry for her."

"The girls are good with him. But he bites them and pulls their hair. They're neglected and have to take second place to their brother."

"This sometimes bothered me. I would shut K out. She began to sit with the doll and talk to it. Now she's a dreamer. I feel a bit ashamed of myself."

"Our older daughter has no escape. None of us can relax. It's very demanding on C."

"J has often said to me, 'You shouldn't have had these two after me. Why do you always talk about M's mummy?'"

"Hard effect on R. He can't enjoy his own childhood as he should. He's always got to take charge of S."

"Her screaming frightened A. He's that wee bit slow after one year at school. A doctor mentioned it might not show up until that time."

The mirror-effect of many of these answers is apparent. The parents told us as often what effect the siblings had had on the handicapped child as vice versa. Nevertheless, we can detect the real deprivation and frustration experienced by many children when one of their number demands a lot of their and their parents' time and affection and 'gives back' very little.

TABLE 52 - 1 PARENTS' ASSESSMENT OF ABILITY TO COPE BY EFFECT OF HANDICAPPED CHILD ON SIBLINGS

	Not well Well + stress	Well - stress	Total
No effect or Not applicable	26	35	61
Good effect	7	28	35
Bad effect	31	17	48
Total	64	80	144

P = less than .01 X^2 = 16.4361

Almost two thirds of the parents (65.4%) claiming the child had a bad effect on the siblings felt that they were not coping well or were coping well with stress (Table 52 - 1).

TABLE 52 - 2 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY EFFECT OF HANDICAPPED CHILD ON SIBLINGS

	Not well ± stress	Well + stress	Well - stress	Total
No effect or Not applicable	3	30	28	61
Good effect	2	15	18	35
Bad effect	9	32	7	48
Total	14	77	53	144

P = less than .01 X^2 = 18.4053

The interviewers ranked 85.4% of the parents who claimed the child had a bad effect on the siblings in the coping not well or coping well with stress categories (Table 52 - 2).

TABLE 52 - 3 MOTHER'S RELATIONSHIP TO CHILD BY EFFECT OF HANDICAPPED CHILD ON SIBLINGS

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No effect	5	8	39	52
Good effect	10	8	17	35
Bad effect	12	17	19	48
Not applicable	3	2	4	9
Total	30	35	79	144

P = less than .02 X^2 = 15.7251

Half the ambivalent mothers consider the child had a bad effect on his siblings (Table 52 - 3).

53. Agency of Most Support	No.	Per cent.
Hospital Doctor	21	14.6
Family Doctor	18	12.5
Health Visitor/District Nurse	16	11.1
Psychologist/Teacher	28	19.4
Social Worker	4	2.8
Voluntary Society	26	18.1
Friends, neighbours	8	5.6
No one/ourselves	24	16.7

54. Agency of Most Information	No.	Per cent.
Hospital Doctor	17	11.8
Family Doctor	9	6.2
Health Visitor/District Nurse	23	15.9
Psychologist/Teacher	47	32.6
Social Worker	5	3.5
Voluntary Society	28	19.4
Friends, neighbours	2	1.4
No one/ourselves	13	9.1

Parents who were pleased with the medical profession as a source of information and support included the following:-

"Dr. X. He will listen and you can talk to him. We can even go out of turn."

"When J was nearly two the health visitor gave advice re the play-group."

"My own G.P. is still one hundred per cent. supportive. The almoner at the clinic moved, and within a week he was in nursery school. They were amazed I hadn't come before. It needed me to make the first move."

"No one has helped me much, but most help and advice from the district nurse."

Psychologists and teachers were beneficial to the following families:-

"His teacher at school has been most helpful. At the Parents' Evening we get progress reports."

"The doctor was no help - 'Oh, boys are always slower than girls' - that wasn't much help. The teachers are doing well and he's coming on fine."

"School teachers and psychologists have been most help."

The only Voluntary Societies we encountered were the Scottish Council for the Care of Spastics (SCCS hereafter) and the Scottish Society for Mentally Handicapped Children (SSMHC hereafter). Amongst the parents who had been helped by these societies, 90% had either spastic or Mongol children. Their appreciatve comments include:-

"The SCCS contacted us as soon as we returned from the Army in Germany. They put us in touch with the nursery."

"SCCS social workers. I dinnae feel I'm left here isolated."

"The hospital sent him to SCCS and they sent social workers and therapists to our home. The health visitor got him into a playgroup. I think one person to give all that sort of advice would be best."

"SCCS and the Day Centre. Although there's a lot of infighting between medical and educational people there."

"SSMHC Edinburgh branch, through the Newsletter and Bulletin. We've literally had no advice on these children except through conversation with other parents."

"SSMHC, although they never talk about what is being done for the under-five's. There's too little background. It's not pragmatic enough for new members. We don't know about all the services."

"Since I've become a member of SSMHC I've been able to accept and cope better. I was on the point of a nervous breakdown. I didn't know a thing until I joined the SSMHC."

The differences between the two Societies may be simply stated. The SCCS, notified by hospital doctors who are honorary consultants to the Society, contacts parents and brings advice and help to the home. The SSMHC, on the other hand, relies on being approached by parents before any help or advice can be offered. It must be possible to evolve a system whereby all parents whose child is clearly mentally handicapped (with or without a physical component) can be put in contact with a voluntary society as soon as the diagnosis is made.

Two comments will suffice to capture the mood of those parents who claimed to have received no information or support:-

"Nobody has shown any particular interest. They diagnosed and discarded. It's been pulling teeth all the time. We've not become bitter, just militant."

"I don't think anybody really has given us any information. We've had to go and dig it out for ourselves."

Before we tabulate some of the significant correlations we would observe that these verbatims give a fair indication of the total sum of counselling and support as reported under Questions 57 and 58. It will be seen that very few parents were being helped to work through their feelings. Not all, of course would want this, but few had the opportunity. That many might have valued such help is suggested by the painful and ?truthful feelings articulated in many homes. However, with this explanatory comment in mind, a measure of caution needs to be shown when considering the relatively high percentage of parents who claim to have had counselling and/or support in the past (see Questions 57 and 58).

TABLE 53 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY AGENCY OF MOST SUPPORT

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Medical	17	29	8	54
Educational	20	7	1	28
Social Work, Voluntary Socy.	12	12	14	38
No one/selves	12	11	1	24
Total	61	59	24	144

P = less than .01 X^2 = 27.8258

A surprising finding is that over half (58.3%) the parents of severely handicapped children felt that the voluntary society, more than the medical profession, offered most support (Table 53 - 1). The tie-up between the SCCS and the hospitals probably accounts for this anomaly.

TABLE 53 - 2 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY AGENCY OF MOST SUPPORT

	More handicapped	Less handicapped	Not tested	Total
Medical	28	13	13	54
Educational	2	22	4	28
Social Work, Voluntary Socy.	13	19	16	38
No one/selves	10	11	2	24
Total	54	55	35	144

P = less than .01 X^2 = 35.9294

Nearly eight in ten parents (78%) claiming most support from educational personnel had children who had been assessed as less handicapped, whereas only 7% of parents whose children had been assessed as more handicapped (i.e. with a child in Gogarburn Hospital, Day Centre,

or a Junior Occupation Centre) felt the educational services were supportive (Table 53 - 2).

TABLE 53 - 3 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY AGENCY OF MOST SUPPORT

	Not well ± stress	Well + stress	Well - stress	Total
Medical	4	33	17	54
Educational	1	11	16	28
Social Work, Voluntary Socy.	6	20	12	38
No one/selves	3	13	8	24
Total	14	77	53	144

P = N.S. $X^2 = 8.5894$

The interviewers assessed as coping well with stress or not well 68% of those parents mentioning medical support, 43% of those claiming educational support, 68% of those mentioning voluntary society support and 66% of those claiming no support (Table 53 - 3). The differences are not significant; more help for more parents for a longer period would nonetheless seem to be indicated.

TABLE 54 - 1 SOCIAL CLASS BY AGENCY OF MOST INFORMATION

	I - II	III	IV - V & Other	Total
Medical	12	17	20	49
Educational	9	17	21	47
Social Work, Voluntary Socy.	2	15	18	35
No one/selves	1	6	6	13
Total	24	55	65	144

P = less than .01 $X^2 = 19.9487$

There is an interesting tendency for parents in Classes I - II not to consult voluntary societies, etc., but to use the medical and educational professions as sources of information; this does not hold good for parents in other Classes (Table 54 - 1).

TABLE 54 - 2 MOTHER'S RELATIONSHIP TO CHILD BY AGENCY OF MOST INFORMATION

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Medical	8	14	27	49
Educational	6	6	35	47
Social Work, Voluntary Socy.	15	10	10	35
No one/selves	1	5	7	13
Total	30	35	79	144

P = less than .01 X^2 = 23.1533

Half the protective, one third of the ambivalent and only one in eight of the accepting mothers rely on voluntary societies for their information (Table 54 - 2). Featuring largely in this category are parents of spastic children.

The only other source of support mentioned by one family was the church, the minister and members of which had been understanding and concerned for the family. This same family also received help and advice from the medical and educational authorities as well as annual holiday relief by admitting the child to Rumbie Village. In this they typify the families who were 'community-' as against 'home-oriented'.

55. Father's Religious Belief	No.	Per cent.
None	61	42.4
Church of Scotland	24	16.7
Roman Catholic	21	14.6
Episcopalian (1) Greek Orthodox (1)	2	1.4
Baptist (1) Congregational (1)	2	1.4
Jehovah's Witness	1	.7
Not known	33	22.9

56. Mother's Religious Belief	No.	Per cent.
None	67	46.5
Church of Scotland	38	26.4
Roman Catholic	27	18.7
Episcopalian	2	1.4
Baptist (5) Congregational (3)	8	5.6
Jehovah's Witness	2	1.4

The question was put in the form, "Do you have any strong religious belief, or are you connected with any church?" We cannot claim that the numbers, small as they are, indicate present and active church membership, but we presume some past connection with the various denominations cited. From a selection of the verbatims we can gauge the extent to which parents felt strengthened or disappointed in their faith in God or connection with the church. Fathers commented:-

"Not now. I was brought up to believe and practise religion. It's a lot of rubbish now. No God could let this happen to bairns."

"I think I believe in God but I feel cheated."

"I had a strong religious upbringing. But now I'm agnostic, atheist even."

"I dinnae go to church, but I believe in Lourdes."

"I suppose I've got religious belief but I'm no churchgoer. I still believe. Having a mentally handicapped child hasn't put me off."

"I'm a church elder and have been for several years."

"I say their prayers each night - they're too young to disillusion. I need proof in my work and in my faith. My sister died when she was 14 and I've never believed since then."

"I'm too practical to expect something divine to change a cold, hard fact on earth."

"It's kind of put me off, having J."

Mother's comments included the following:-

"I made a bargain with God, 'You make him better and I'll believe.' I started going to church a year ago due to depression."

"Since this has happened to G there's no such person as God."

"Not now. I hope it comes back at some time."

"She was mine, and although it was a shock, God must have given me her for a purpose."

"I used to have, but I wondered why ...?"

"Our church fellowship has given us a lot of support."

"I have my doubts because of A."

"When J was born I said there was nothing of the sort. You have to take it out on somebody..."

"I felt God had let me down, but you get over it in time."

"I would say 'Yes' as opposed to 'No'. I don't go regularly to church, but I do a bit of praying from time to time. The minister was supportive when needed.

"I'm sure that's what pulled me through."

"I've no turned to church since A. I've become a bit bitter."
"I used to be a church organist. I am now an atheist, but hope I am wrong."
"We'd never have got through without help from somewhere. We got our support from God. There was nobody you could talk to."
"I'm a staunch Catholic, rarely out of the church. I've no money, no friends, so I have to hold on to something."
"The church was not a great deal of help. The minister would come and not discuss G; it saved my tears, he said."
"You have belief and some hope. You never give up. Miracles happen."

Quite clearly, the majority of parents giving thought to this possible source of help felt cheated, disappointed or disillusioned. Fathers were noticeably more dismissive of the church, mothers proportionately more grateful for inner help, but mainly unimpressed with the church as a caring community. In all, three ministers were mentioned in the entire interview, two having proved helpful, one evasive. The small number is more revealing than the ratio of helpful to unhelpful ministers. We believe the case has been demonstrated for far greater involvement by the clergy and congregation in supporting families with a mentally handicapped child.

We divided the mothers into Protestant, Catholic and No religion groups and analysed them by 16 factors but revealed no significant differences in distribution. The only slightly significant trend we could detect is given in the following table.

TABLE 56 - 1 COUNSELLING/SUPPORT NOW BY MOTHER'S RELIGION

	Medical	Educational	Voluntary Society	None	Total
Protestant	6	10	6	28	50
Catholic	2	2	9	14	27
No religion	10	3	8	44	67
Total	18	15	23	86	144

P = less than .05 X^2 = 14.8607

The interpretation is unclear as well as the numbers being small, but Table 56 - 1 reveals the following factors:- profession of some religion links with greater utilization of the counselling/support systems available; whereas slightly over one half of both Protestant and Catholic mothers claim no help from the counselling/support services, this rises to two thirds of the mothers with No religion. This might support the belief that religious profession has to do with admitting dependency needs and accepting help in the satisfying of such needs. Between the religious groupings it is noticeable that Protestant mothers are over-represented in the educational counselling/support system, Catholic mothers in the voluntary societies' counselling/support system. Insofar as Protestant mothers see education as potentially a change-agent in their child's life chances, and insofar as Catholic mothers see voluntary societies as acceptance-oriented agencies to support an unalterable situation, we suggest that a popular belief is being demonstrated. Non-religious mothers would seem to pin their faith on the medical profession. Above all, however, we qualify the foregoing remarks by reiterating the smallness of the numbers involved and the uncertainty that we are here dealing with 'practising Christians'.

57. Counselling in Past	No.	Per cent.
No	80	55.6
Yes	64	44.4

58. Support in Past	No.	Per cent.
No	60	41.7
Yes	84	58.3

The meaning of the word "counselling" had to be explained in the vast majority of homes, it being no part of the parents' usual vocabulary. We defined it as, "Did you feel that as well as someone being around who gave you advice, there was someone you could turn to for emotional support and help?"

It was at this point in the interview that the significance of the presence of physical handicap became clearer, the first hint of which appears prior to Table 19 - 1. Accordingly, we correlated the distribution of counselling and support in the past by the presence or absence of physical handicap.

TABLE 57 & 58 - 1 DEGREE OF PHYSICAL HANDICAP OF CHILD BY COUNSELLING AND/OR SUPPORT IN THE PAST

	Some/severe physical handicap	No physical handicap	Total
Counselling + Support	23	10	33
Counselling only	5	2	7
Support only	20	10	30
No Counselling or Support	12	62	74
Total	60	84	144

P = less than .001 X^2 = 40.6531

Table 57 & 58 - 1 demonstrates the imbalance between the 80% of parents with a mentally handicapped child who is physically handicapped who felt they had received counselling/support in the past, and the 26.2% of parents with a non-physically handicapped mentally retarded child who felt they had received such help in the past.

Parents of physically handicapped retarded children commented:-

"Looking back on it, I think we've had our fair share of help. If we'd been younger, or if it had been our first child, it would have been terrible."

"I can pick up a 'phone and get any help I need from the SCCS. Unlike a friend who has a Mongol; she felt very overlooked and forgotten."

"I joined the West Lothian branch of SSMHC. I found it very helpful, parents of children the same age as yours and older, who have faced these problems already. I'm now a committee member, but some parents won't join for love nor money. One mother said to me, 'Don't you wish the doctor would put them to sleep?' I said, 'Is it a dog you have?'"

"Nobody came near us at the beginning. We thought he was ours for life. All our spare time was anxious and short-lived until he went into play group at four years old. The mothers need a break before the child is four."

"I kept things to myself and so resisted support, until a virtual breakdown forced me to become open to others. Joining the SSMHC helped me."

"Counselling wasn't done well to begin with. There should be some form of help on the management of such children, what to expect, etc. We have more or less plodded along ourselves."

Parents of non-physically handicapped retarded children commented:-

"I've been to see Dr. X and she's taken notes and listened. All the people I've met have listened, done tests, spent time; but couldn't suggest anything further on the National Health Service. Now it's an educational problem."

"The main complaint is that no one would face us with the problem. I met all the teachers in my professional capacity as a bank manager or on committees. Maybe they feared our reactions, but we feel we might have been told earlier. I prefer facing facts and would like to know the truth. I feel awfully blind now that I didn't see things as they were and realise how backward he was at one stage."

"A lady doctor said to me, 'A lot depends on your attitude. He'll be a handicapped child if you treat him like one.'"

"Our own immediate family. Our G.P. Hasn't been much good. He always says, 'He's a Mongol, what can you expect?' It gets a bit annoying."

"It's mostly been self-counselling. We've accepted him as a child from God."

"I think we could do with more support, advice and information. There's lack of a place to go to find out."

"We could have done with more support, and advice, in the early stages. Now he's in the system it's O.K. But who is the first link?"

"You learn as you go along, but with two mentally handicapped boys you can't afford to make too many mistakes. On our last three visits to the hospital we've seen three different doctors. It wastes time covering the same ground over and over again. With a mentally handicapped child it would be better to have one, or two doctors at most."

"A lot of mothers in SSMHC say we need more people to come and visit us in our homes to see how we're coming on and give us encouragement."

Summarising this selection from a total of 92 extended verbatims, the parents pinpoint the following areas for possible improvement:- centralising the source of information in the form of a multi-disciplinary clinic; bringing the bearers of advice and help into the home, and priming the family doctors on the available facilities.

TABLE 57 - 1 SOCIAL CLASS BY COUNSELLING IN THE PAST

	I - II	III	IV - V & Other	Total
No	12	38	30	80
Yes	12	17	35	64
Total	24	55	65	144

P = less than .01 X^2 = 9.7819

Analysed by social class (Table 57 - 1), exactly half the parents in Classes I - II, slightly under half the parents in Classes IV, V and Other, and seven in ten parents in Class III claim to have received no counselling in the past. This sense of frustration in Class III parents might point to their distress at the child's hampering of their upward mobility. The fact that over half the Classes IV, V and Other families have received counselling in the past is surprising; in many cases, however, the help they received came from within the family circle rather than from external sources.

TABLE 58 - 1 PARENTS' ASSESSMENT OF ABILITY TO COPE BY COUNSELLING IN THE PAST

	Not well ± stress Well + stress	Well - stress	Total
No	32	28	60
Yes	32	52	84
Total	64	80	144

P = less than .02 X^2 = 5.6425

That parents did appreciate the support they received, whether from spouses, relatives, neighbours, fellow-parents or professionals is suggested by Table 58 - 1. Almost two thirds (65%) of those with past support felt they were coping well without stress, whilst only half those coping not well or well with stress had received such past support.

59. Playgroup or Nursery School in the Past	No.	Per cent.
No	42	29.2
Yes	102	70.8

TABLE 59 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY CHILD IN PLAYGROUP/NURSERY SCHOOL IN THE PAST

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	22	11	9	42
Yes	39	48	15	102
Total	61	59	24	144

P = greater than .05 $X^2 = 5.3737$

The majority of parents had made use of these provisions, but this applied to only 62.5% of parents with severely handicapped children, as Table 59 - 1 indicates. In part this may be due to the difficulty of establishing suitable facilities for the more profoundly handicapped, in part because this group included the nine who had hospitalised their child, and for the rest there were some mothers in this group who were over-protective towards their child and so might not have used any services which were provided.

TABLE 59 - 2 SOCIAL CLASS BY CHILD IN PLAYGROUP/NURSERY SCHOOL IN THE PAST

	I - II	III	IV - V	Other	Total
No	5	16	10	11	42
Yes	19	39	28	16	102
Total	24	55	38	27	144

P = N.S. $X^2 = 2.7057$

Social class analysis shows that the children of nearly 80% of Classes I - II parents had been in playgroups or nursery schools, compared with only 32% of children from Classes IV, V and Other homes; the differences do not reach significant levels (Table 59 - 2).

60. Day Centre in the Past	No.	Per cent.
No	126	87.5
Yes	18	12.5

TABLE 60 - 1 SEX OF CHILD BY CHILD IN DAY CENTRE IN THE PAST

	Male	Female	Total
No	79	47	126
Yes	17	1	18
Total	96	48	144

P = less than .01 $X^2 = 5.7855$

Further evidence that more boys were in the more handicapped group than girls - in the families we interviewed - is given in Table 60 - 1. Only one girl had been in a Day Centre, the provision for the multiply or profoundly handicapped children who lived at home.

61. Child in Hospital in the Past	No.	Per cent.
No	36	25.0
Yes, for less than 3 months	80	55.6
Yes, for 3 - 6 months	8	5.6
Yes, for more than 6 months	20	13.9

The last category included all nine Gogarburn Hospital patients. We hoped to determine from this question how much Gogarburn Hospital had been used for holiday or relief admission, but before we could explain our intentions, we heard from the parents the usual run of childhood illnesses and accidents. Disappointed in not eliciting the sort of information we desired, we were interested to discover that 75% of the children had spent some time in hospital other than the peri-natal period. Most parents who elaborated on their answer to this question praised the quality of general hospital care and were especially appreciative of the new attitudes towards visiting hours for parents. Though many of the children were burdensome, parents did not like being separated from them for long.

SECTION IV DATA ON PRESENT SITUATION AND NEEDS MET

62. Housing	No.	Per cent.
Owner-occupier	36	25.0
Rented property	11	7.6
Tied property	4	2.8
Corporation (Edinburgh) or Council (W. Lothian)	90	62.5
Emergency housing (2) Condemned housing (1)	3	2.1

TABLE 62 - 1 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY TYPE OF HOUSING

	More handicapped	Less handicapped	Not tested	Total
Owner-occupier	22	13	1	36
Corporation	29	37	24	90
Other	3	5	10	18
Total	54	55	35	144

P = less than .01 X^2 = 23.1589

When analysed by psychologist's assessment, 41% of families with more handicapped children lived in private housing, whilst 62% of families with less handicapped children lived in Local Authority housing (Table 62 - 1).

63. Total Family Weekly Income	No.	Per cent.
Less than £12	2	1.4
£12 - £19	32	22.2
£20 - £34	83	57.6
£35 and more	27	18.7

TABLE 63 - 1 SOCIAL CLASS BY TOTAL FAMILY WEEKLY INCOME

	I - II	III	IV - V & Other	Total
Under £20	1	7	26	34
£20 - £34	4	42	37	83
£35 and over	19	6	2	27
Total	24	55	65	144

P = less than .01 X^2 = 105.6228

Correlating income with social class produced the expected distribution, though almost one quarter of the families claimed a take-home income of £19 or less per week (Table 63 - 1).

TABLE 63 - 2 MOTHER'S RELATIONSHIP TO CHILD BY TOTAL FAMILY WEEKLY INCOME

	Protective Exclusive	Ambivalent Rejecting Witndrawn	Accepting	Total
Under £20	5	4	25	34
£20 - £35	20	26	37	83
£35 and over	5	5	17	27
Total	30	35	79	144

P = greater than .05 X^2 = 9.4434

Almost three quarters (74%) of ambivalent or rejecting mothers came in the middle income bracket, whilst just under half (47%) of accepting mothers were in that bracket; these differences did not reach significane (Table 63 - 2).

64. Special Attendance Allowance	No.	Per cent.
No	117	81.2
Yes	27	18.7

Originally this question was phrased, "Are you receiving any help at present with the child?" The eighth family we saw mentioned the Special Attendance Allowance, and the question was asked with this new meaning in all subsequent interviews. We wrote to the seven families already interviewed and received their answers to the question in its new form. The Special Attendance Allowance is for severely handicapped children who require day and night attendance because of their incapacity or their need for protection from injury inflicted by them or on them. Despite the fact that a publicity campaign had been under way for six months before our first interview, many parents had not heard of it. Many deserving families (as the researchers saw them) had caustic comments to make on the system; the unfeeling nature of counter-clerks in Social Security offices, the aloofness of the decision makers in Blackpool, and the lack of perseverance shown by their family doctor in pressing home their claim for the allowance, all came under fire. One father graphically expressed the indignation felt by many families when he said, "I've written to them at Blackpool to come and be my guest for a week, even offering to pay their train fare, and let them decide at the end of it whether T needs constant attendance."

TABLE 64 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY FAMILY RECEIVING SPECIAL ATTENDANCE ALLOWANCE

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	55	48	14	117
Yes	6	11	10	27
Total	61	59	24	144

P = less than .01 X^2 = 11.4543

Only 42% of the families of severely handicapped children were receiving this allowance, although such parents who had hospitalised their child were of course ineligible for it (Table 64 - 1).

TABLE 64 - 2 SOCIAL CLASS BY FAMILY RECEIVING SPECIAL ATTENDANCE ALLOWANCE

	I - II	III	IV - V & Other	Total
No	17	46	54	117
Yes	7	9	11	27
Total	24	55	65	144

P = N.S. $X^2 = 3.0805$

The social class differences are not significant, but it is noticeable that the highest proportion of families (29%) receiving the Special Attendance Allowance were in Classes I - II (Table 64 - 2). We know from other tables that the more handicapped children tend to cluster in these Classes; nevertheless, it is a touch ironic that those who do not perhaps always need the extra money and might prefer intangible benefits such as emotional compensation, manage to obtain the Allowance, whilst those families in which the child's current drain on the income and eventual inability to earn has financial dimensions, cannot argue their case well enough or are not aware of their rights to the Allowance.

TABLE 64 - 3 MOTHER'S RELATIONSHIP TO CHILD BY FAMILY RECEIVING SPECIAL ATTENDANCE ALLOWANCE

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No	20	28	69	117
Yes	10	7	10	27
Total	30	35	79	144

P = less than .05 $X^2 = 6.1479$

The maternal relationship to the child was analysed in those families receiving the Allowance (Table 64 - 3). One third of the protective/

exclusive mothers, compared with one fifth of the ambivalent/rejecting mothers were in receipt of the Special Attendance Allowance.

65. Counselling/Support in the Present	No.	Per cent.
No	86	59.7
Medical personnel	18	12.5
Educational personnel	15	10.4
Local Authority Social Worker	2	1.4
Voluntary Society, friends, etc.	23	15.9

The trend noted earlier, for parents with a physically handicapped retarded child to receive more counselling and support than other parents in the past, still holds good.

TABLE 65 - 1 PHYSICAL HANDICAP IN CHILD BY PAST COUNSELLING

	Physically handicapped	Not physically handicapped	Total
No	12	62	74
Yes	48	22	70
Total	60	84	144

P = less than .001 X^2 = 40.5677

TABLE 65 - 2 PHYSICAL HANDICAP IN CHILD BY PRESENT COUNSELLING

	Physically handicapped	Not physically handicapped	Total
No	24	62	86
Yes	36	22	58
Total	60	84	144

P = less than .001 X^2 = 16.6319

Tables 65 - 1 and 65 - 2 demonstrate the high correlation between having a physically handicapped retarded child and receiving proportionately more counselling and support than parents of other mentally handicapped children.

We account for the lower proportion of parents with physically and mentally handicapped children who are satisfied with counselling now (60%) than were satisfied with counselling in the past (80%) on the grounds that the parents now dissatisfied had earlier claimed support from within the family circle, and this had now either diminished or was not of itself sufficient to meet their needs. In any case, these parents seem privileged both past and present in comparison with all other parents, 68.6% of whom were unsupported in the past, 73.7% claiming no counselling/support at present.

The nature of the counselling received at present is tabulated below:-

TABLE 65 - 3 PHYSICAL HANDICAP IN CHILD BY IDENTITY OF PRESENT COUNSELLING/SUPPORT AGENCY

	Physically handicapped	Not physically handicapped	Total
None	24	62	86
Medical	14	4	18
Educational	4	11	15
Social Work, Voluntary Socy.	18	7	25
Total	60	84	144

P = less than .001 X^2 = 27.2085

The connection between the SCCS and the hospitals accounts for the high proportion of parents in the first category claiming help from a voluntary society; as expected, the educational profession offered most help to the parents whose child was mentally but not physically handicapped (Table 65 - 3).

One or two comments from satisfied parents will disclose the very sketchy nature of the counselling they receive and yet appreciate:-

"The Social Worker, speech therapist and physiotherapist from SCCS are all good."

"The District Nurse comes in once a week to clean out her bowels, the physiotherapist comes twice a week, and we can talk."

"The G.P. is pleased when he sees J, and he's always available for us to see him."

"The hospital are thrilled with her. She's demonstrated in lectures and made the centre of attention every time she goes there."

"His Headmistress at nursery school is very good."

"Speech therapy at school is the best help."

"The Parents' Evening at the special school."

"You can visit the physiotherapist at his school (run by SCCS), watch them exercising him, learn, and copy it at home."

"I have eight people a day to assist with the Doman Delacato programme. An army of 50 volunteers in all have been taught how to help."

"Mrs. Y - a neighbour - and through her the SSMHC she introduced me to."

From the foregoing sample we deduce that the counselling and support parents value most includes friendship, service rendered, advice given and visits to the home by the professionals, or to the school or hospitals by the parents. The satisfied parents include six of the nine with a child in Gogarburn Hospital (the other three being more hostile in attitude), thereby reducing to 12 the number of parents with a child at home who are being supported or advised satisfactorily by the medical profession.

TABLE 65 - 4 SOCIAL CLASS BY COUNSELLING/SUPPORT NOW

	I - II	III	IV - V & Other	Total
No	15	27	44	86
Medical	3	6	9	18
Educational, Social Work, Voluntary Socy.	6	22	12	40
Total	24	55	65	144

P = greater than .05 X^2 = 11.0047

Table 65 - 4 shows that 37% of Classes I - II families as opposed to 32% of Classes IV, V And Other families are getting counselling/ support at present, but the numbers are small and the differences are not significant.

TABLE 65 - 5 MOTHER'S FAMILY SIZE PLANS BY COUNSELLING/SUPPORT NOW

	No effect	No more children	Other	Total
No	58	18	10	86
Medical	9	6	3	18
Educational, Social Work, Voluntary Socy.	20	19	1	40
Total	87	43	14	144

P = less than .05 X^2 = 14.5119

Family size plans seem to be related to whether or not the mothers are currently getting counselling/support; 67% of mothers who said that the handicapped child had no effect on family size plans are not getting counselling/support, whereas 58% of mothers who had decided to have no more children are getting counselling/support (Table 65 - 5).

TABLE 65 - 6 DEGREE OF MENTAL HANDICAP OF CHILD BY COUNSELLING/SUPPORT NOW

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	41	37	8	86
Medical	5	6	7	18
Educational, Social Work, Voluntary Socy.	15	16	9	40
Total	61	59	24	144

P = greater than .05 X^2 = 11.1271

The majority of families with a severely handicapped child were getting counselling/support whilst the majority who thought there was no handicap or were not sure were not getting counselling/support at present (Table 65 - 6).

66. Child presently in Playgroup, Nursery School or Day Centre	No.	Per cent.
No	98	68.1
Playgroup	11	7.6
Nursery School	19	13.2
Day Centre	16	11.1

TABLE 66 - 1 MOTHER'S FAMILY SIZE PLANS BY CHILD PRESENTLY IN PLAYGROUP, NURSERY SCHOOL OR DAY CENTRE

	No effect	No more children	Other	Total
No	66	20	12	98
Playgroup or Nursery School	18	11	1	30
Day Centre	3	12	1	16
Total	87	43	14	144

P = less than .01 X^2 = 21.7921

Table 66 - 1 reveals, what might be expected, that mothers with a child in a Day Centre were over-represented in the group who had decided to have no more children.

TABLE 66 - 2 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY CHILD PRESENTLY IN PLAYGROUP, NURSERY SCHOOL OR DAY CENTRE

	Not well ± stress Well + stress	Well - stress	Total
No	60	38	98
Playgroup, Nursery School	16	14	30
Day Centre	15	1	16
Total	91	53	144
	P = N.S.	X^2 = 7.8397	

TABLE 66 - 3 PARENTS' ASSESSMENT OF ABILITY TO COPE BY CHILD PRESENTLY IN PLAYGROUP, NURSERY SCHOOL OR DAY CENTRE

	Not well ± stress Well + stress	Well - stress	Total
No	43	55	98
Playgroup, Nursery School	10	20	30
Day Centre	11	5	16
Total	64	80	144
	P = N.S.	X^2 = 5.3407	

Tables 66 - 2 and 66 - 3 do not show significant differences, but in the former table the interviewers placed all but one family with a child in Day Centre in the coping not well or well with stress category; in the latter table two thirds of the parents with a child in Day Centre classified themselves as similarly coping not well or well with stress.

67. Child presently in Cogarburn Hospital	No.	Per cent.
No	135	93.7
Yes	9	6.2

The nine 'patients' were all boys, two of them only, three oldest, one youngest and three middle children. Five of them were under 5 years of age. Six of the parents expressed gratitude and relief at his placement there, the staff care and relationships on visits, etc. The three families who were more ambivalent about the state of affairs, critical of parent-staff liaison, quality of services provided, etc., had in two cases their only child and in one case their youngest child (and only son) in hospital.

68. Child presently in Special School, Special Class or Junior Occupation Centre	No.	Per cent.
No	63	43.7
Special School (Edinburgh)	37	25.7
Special Class (West Lothian)	11	7.6
Junior Occupation Centre	33	22.9

We can now list the present placement of the child in two tables, the first by the psychologist's assessment, the second by the parents' estimate of the degree of the child's handicap. This will afford the opportunity for comparing psychologically measured and parentally estimated degrees of mental handicap, identifying the areas of most discrepancy and offering an opportunity to interpret any anomalies which may feature in the two tables.

TABLE 66, 67, 68 - 1 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY CHILD'S PRESENT PLACEMENT

	More handicapped	Less handicapped	Not tested	Total
At home	0	4	4	8
In Gogarburn Hospital	9	0	0	9
Playgroup/Nursery School	1	7	22	30
Day Centre	9	4	3	16
Junior Occupation Centre	33	0	0	33
Special School/Class	2	40	6	48
Total	54	55	35	144

TABLE 66, 67, 68 - 2 DEGREE OF MENTAL HANDICAP OF CHILD BY CHILD'S PRESENT PLACEMENT

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
At home	4	4	0	8
In Gogarburn Hospital	0	2	7	9
Playgroup/Nursery School	11	15	4	30
Day Centre	3	5	8	16
Junior Occupation Centre	6	23	4	33
Special School/Class	37	10	1	48
Total	61	59	24	144

The most obvious discrepancies between psychologically measured and parentally estimated degrees of mental handicap cluster around parents with children in Junior Occupation Centre or in Special School/Class (Tables 66, 67, 68 - 1 and 66, 67, 68 - 2). Almost seven in ten (69%) of the parents with children in J.O.C. admit to some degree of mental handicap but only one in ten (12%) admit to severe mental handicap.

Only one in five (20.8%) of the parents with children in Special School/Class admit to some degree of handicap and (probably correctly) only one in 48 (2%) admits to severe mental handicap.

We have already noted that in the majority of cases of severe mental handicap the parents are told by the doctor (Table 37 - 4) before the child is 3 years old (Table 37 - 1) and that parents of multiply handicapped children (Table 39 - 3) and of Mongols (Table 39 - 5) remember the interview as unsatisfactory. This group of parents, however, accord by and large with the psychologist's assessment insofar as most multiply handicapped children go to a Day Centre and most Mongols go to a Junior Occupation Centre; parents of Day Centre attenders denied handicap or suspended judgment in only 20% of cases, parents of J.O.C. attenders in only 18.1% denied or suspended judgment on the child's handicap. On the other hand, the majority of parents with mildly handicapped children are told by the psychologist (Table 37 - 4) after the child has entered school (Table 37 - 1) and that by social class analysis (Table 39 - 1) parents in Classes IV, V and Other are proportionately more satisfied with the diagnostic interview. This group of parents, however, repudiate or ignore or forget the psychologist's assessment insofar as their children go predominantly to Special School/Class, and 77% of such parents deny or suspend judgment on their child's handicap.

It is becoming apparent that parents 'hear' what the doctor is saying to them, dislike it and are often critical of the manner of telling, but are more prepared to hear a confirmatory diagnosis in similar terms at a later date from the psychologist. Conversely, parents fail to 'hear' what the psychologist is saying to them, do not find it disturbing or memorable, and act as if the information was either not given or was given but incorrect. What we cannot know is whether

the second situation would be altered by a doctor making the diagnosis even of mild mental handicap; it is at least arguable that it would, since few parents contradict or doubt doctors.

TABLE 68 - 1 ORDINAL POSITION OF CHILD BY CHILD IN J.O.C. OR SPECIAL SCHOOL/CLASS

	Oldest/Only	Youngest	Middle	Total
No	14	33	16	63
J.O.C.	12	15	6	33
Special School/Class	7	18	23	48
Total	33	66	45	144

P = less than .02 X^2 = 12.1495

Table 68 - 1 indicates that of the 63 not placed children 33 are youngest children, and a total of 44 are known to be under 5 years old; half the children in Special School/Class are middle children.

TABLE 68 - 2 HANDEDNESS OF CHILD BY CHILD IN J.O.C. OR SPECIAL SCHOOL/CLASS

	Left/Both handed	Right handed	Total
No	24	34	58
J.O.C.	18	15	33
Special School/Class	15	33	48
Total	57	82	139

Excluded are the five Cogarburn Hospital children with "no grip"

P = less than .02 X^2 = 8.1977

Right handedness is clearly associated with a greater probability of attending a Special School/Class (Table 68 - 2).

TABLE 68 - 3 SOCIAL CLASS BY CHILD IN J.O.C. OR SPECIAL SCHOOL/CLASS

	I - II	III	IV - V & Other	Total
No	7	26	30	63
J.O.C.	9	11	13	33
Special School/ Class	8	18	22	48
Total	24	55	65	144

P = less than .01 X^2 = 11.5103

In Table 68 - 3, social class analysis indicates that children from Classes I - II have a better prospect of placement (73% of these children are placed in J.O.C. or Special School/Class) but that severity of handicap is evenly distributed.

TABLE 68 - 4 PARENTS' ASSESSMENT OF ABILITY TO COPE BY CHILD IN J.O.C. OR SPECIAL SCHOOL/CLASS

	Not well ± stress Well + stress	Well - stress	Total
No	32	31	63
J.O.C.	17	16	33
Special School/ Class	15	33	48
Total	64	80	144

P = N.S. X^2 = 5.0807

There is a trend which does not reach significance for parents with a child in Special School/Class to assess themselves as coping well without stress (Table 68 - 4).

69. Home Help	No.	Per cent.
No	138	95.8
Private Help	6	4.2

Not one family of the 144 was receiving the services of a L.A. Home Help and none volunteered the information that they ever had received such help. Whilst we cannot argue from silence we believe some domiciliary relief and help would be valued by many mothers. Laundry facilities for mothers with incontinent children, for instance, would meet a real need, although only one mother specified this as an unmet need.

70. Baby-sitting available	No.	Per cent.
No	41	28.5
Yes, and used	95	65.9
Yes, not used	6	4.2
Not needed (the only child a Cogarburn patient)	2	1.4

TABLE 70 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY BABY-SITTING AVAILABLE

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	24	14	3	41
Yes and used	35	42	18	95
Yes not used and not needed	2	3	3	8
Total	61	59	24	144

P = greater than .05 X^2 = 9.0474

Two thirds of the parents were able to get occasional evenings out, mainly by using their older children or other relatives as baby-sitters; almost all the parents of severely handicapped children (88%) were satisfied on this count, whilst less than two thirds (61%) of the

parents with children whose handicap was mild or denied had baby-sitting services available. The differences are not quite significant (Table 70 - 1).

TABLE 70 - 2 SOCIAL CLASS BY BABY-SITTING AVAILABLE

	I - II	III	IV - V & Other	Total
No	2	12	27	41
Yes and used	19	41	35	95
Yes not used and not needed	3	2	3	8
Total	24	55	65	144

P = less than .01 X^2 = 16.9928

Baby-sitting was available for 92% of Classes I - II parents as opposed to 58% of Classes IV, V and Other parents (Table 70 - 2).

The parents who could have used baby-sitters but did not were uncertain that any surrogate parent-figure could safely settle down their child. In this connection we first heard an oft-repeated plea for a service of trained day-time child minders which would enable the mother to go out for a shopping expedition, visit to the library, hair-dresser, etc.

71, Problems in Caring for the Child	No.	Per cent.
Dental care	11	7.6
Hair cutting, bath-ing	13	9.1
Care of clothes	5	3.5
Heavy to carry	13	9.1
Bored, destructive, no friends for playing with	23	15.9
No special problems	79	54.9

Parents of Mongol children and epileptic children had most complaints about dental care; the first group because of complications in anaesthetic procedures connected with the child's heart murmur, etc, the second group because of the effects of stabilising drugs on the child's teeth and gums.

One family in West Lothian said:-

"Couldn't West Lothian do something like Edinburgh's mobile dental clinic which serves Special Schools?"

On hair-cutting as a child-care problem these comments were made:-

"She needs one to hold her hands, one to hold her legs, one to hold her head and one to cut her hair."

"He gets touchy when the barber gets near his valve."

Hard wear on clothes affected mostly the children who couldn't walk and consequently wore out trousers, tights, etc. One exceptional case was the child whose parents said he had Moby syndrome, perpetual slavering; his mother complained:-

"He needs to be changed, vest, shirt, pullover and anorak four times a day. As he gets older the clothes get dearer."

Behaviour problems were experienced by these parents, for example:-

"Destructive. Caused one hundred and fifty pounds worth of damage to the house by spreading paint around. Flings trousers and shoes on the fire. Tried to set the kitchen alight. I have to switch off the electricity at the mains every night."

"He's a bit of a problem. He takes tantrums, turns over furniture, throws a knife, hits the other kids with a steel bar."

"He can't wash, dress or feed himself. All he might do is move around more as he gets older. He bites his arm spasmodically and it lasts for weeks. He takes splints off his arms or throws himself out of his cot. He seems to want to hurt himself."

"The other kids have assessed him and want nothing to do with him. He has no boys to play with."

One final example highlights the anguish felt and resilience shown by certain families in caring for the child at home:-

"You think you'd get used to it, him fitting every two months, but you don't. I'm nearly always on my own. The telephone kiosks are usually broken and it means long walks and delays. In the end I take him to hospital to save time. They've told us that any seizure could be the last one..."

None of these parents, of course, have hospitalised their child.

TABLE 71 - 1 MOTHER'S FAMILY SIZE PLANS BY PROBLEMS IN CARING FOR CHILD

	No effect	No more children	Other	Total
Dental care, Hair cutting, hard on clothes	11	18	0	29
Heavy to carry, Bored, destructive, travel on 'buses	19	14	3	36
No special problems	57	11	11	79
Total	87	43	14	144

P = less than .01 X^2 = 26.6767

Whereas 65.5% of mothers who claim there has been no effect on family size plans also claim to have no special problems in caring for the child, 75% of mothers who have decided to have no more children are experiencing problems in caring for the child (Table 71 - 1).

TABLE 71 - 2 DEGREE OF MENTAL HANDICAP OF CHILD BY PROBLEMS IN CARING FOR CHILD

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Dental care, Hair cutting, hard on clothes	6	17	6	29
Heavy to carry, Bored, destructive, travel on 'buses	12	18	6	36
No special problems	43	24	12	79
Total	61	59	24	144

P = less than .02 X^2 = 12.0932

More than two thirds of parents who did not regard the child as mentally handicapped or were not sure, claimed to have no problems in caring for the child (Table 71 - 2).

TABLE 71 - 3 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY PROBLEMS IN CARING FOR CHILD

	Not well ± stress Well + stress	Well - stress	Total
Dental care, Hair cutting, hard on clothes	20	9	29
Heavy to carry, Bored, destructive, travel on 'buses	28	8	36
No special problems	43	36	79
Total	91	53	144

P = less than .05 X^2 = 6.3152

The interviewers placed over half the parents (52.7%) with current child care problems in the coping not well or well with stress group, whilst under one third (32%) were coping well without stress with similar child care problems (Table 71 - 3).

72. Effect of Child on Marital Relationship	No.	Per cent.
Agree, brought us closer together	23	15.9
Agree, taken us further apart	11	7.6
Disagree	8	5.6
Unauteable (one spouse, 14: one informant, 30)	44	30.6
No effect	58	40.3

These parents represent those marriages which had been brought closer together by the presence of the handicapped child:-

"M: I think they bring you closer together; that's part of life. F: I agree."

"M: I still cannae stand him! No, it does bring you closer. F: Yes, I'll come home rather than go to the pub for a pint."

"F: We often sit and discuss her. There's an affinity between us that maybe wouldn't have been there."

"F: At first we nagged each other, but now we've accepted him there's a big improvement."

Parents who admitted to drifting apart over the child commented:-

"You should have been here the other day! It's getting worse since K's been getting troublesome. We can rarely go out together."

"F: We argue more because I pick on him more than the rest."

"F: We argue a lot and have no social life. She hits him and I tell her he can't help it. She's had to give up her work and I've had to lose money at work by coming off the coal face to the surface in order to look after him."

"M: In my opinion he's driven us further apart. F: Not that the child can help it, but we shout at each other more often."

It is evident from this second group of verbatims that there was some disagreement between the spouses, and this is even more evident in

the comments of two families falling in the 'Disagree' category:-

"M: He's too soft on him. F: She's too hard on him. M: He must be made to do things for himself."

"F: Are you driving at any particular aspect of married life? (At this point Mother left to put the children to bed). She does go through stress at times; the effort of two handicapped boys makes her tired by evenings. It puts a lot of physical strain on the marriage."

There would seem to be a case for counselling services to be made available to families where a handicapped child is liable profoundly to alter the dynamics of the marriage. This could take the form of genetic counselling, advice on institutionalisation of the child for the greatest good of the greatest number, or more traditional marriage guidance counselling. We recognise that in certain families there are disruptive forces at work before the handicapped child is born, and that the child can serve as a scapegoat for the parents. Nevertheless, if the families for whom counselling would be useful could be identified in time, such a service would enhance the quality of home life for all the family members.

TABLE 72 - 1 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY EFFECT OF CHILD ON MARITAL RELATIONSHIP

	Not well ± stress	Well + stress	Well - stress	Total
Agree, brought us closer	1	15	7	23
Agree, taken us apart	6	5	0	11
Disagree (8) Unrateable (44)	5	28	19	52
No effect	2	29	27	58
Total	14	77	53	144

P = less than .01 X^2 = 32.4223

The interviewers placed 30% of the 'closer together' marriages in the coping well without stress category, but none of the 'further apart' marriages in that category (Table 72 - 1).

TABLE 72 - 2 MOTHER'S FAMILY SIZE PLANS BY EFFECT OF CHILD ON MARITAL RELATIONSHIP

	No effect	No more children	Other	Total
Agree, brought us closer	12	10	1	23
Agree, taken us apart	5	2	4	11
Disagree (8) Unrateable (44)	31	17	4	52
No effect	39	14	5	58
Total	87	43	14	144

P = less than .05 X^2 = 12.8317

Table 72 - 2 indicates that in almost half the 'closer together', one in three of the 'disagree/unrateable', and one in five of the 'further apart' marriages the mother had decided to have no more children. We suggest that the high proportion of 'closer together'

marriages in which the mother had decided to have no more children could indicate a potentially too-cohesive family structure in which the handicapped child has given the parents 'a cause worth living for.' This is a tentative hypothesis based on a small sample, however, and must be qualified by that fact.

73. Effect of Child on Father's Family Size Plans	No.	Per cent.
No effect	71	49.3
No more children	26	18.1
Must have another to make up	8	5.6
Other (2 deceased) and Not known	39	27.1

The small group who wanted another to make up for the disappointment of the handicapped child included this father:-

"I wanted another and damn the consequences. I'm a risk taker."

Those who claimed that the child had had no effect commented:-

"That's a medical thing. I was tested for it and cleared. You take your chance like the rest of the population."

"We had tests and these were O.K. We needed reassuring it wouldn't happen again."

The fathers who had decided to have no more children remarked:-

"We're getting abit past it now, and are also afraid of a repeat. We both decided to get sterilised because of D."

"We've thought about this a lot, discussed it endlessly. We couldn't even go in for adoption because the Adoption Society wouldn't like A."

"I think we've had enough of a handful with K. My wife would worry through the pregnancy, and underneath, I suppose I would."

"I think myself two's a nice size of family. But it's a pity it has happened."

In view of the small numbers involved we merely record that of the eight fathers who wanted another child to make up for the handicapped child all had boys, in three quarters of the cases severely handicapped and in half the cases an only child.

TABLE 73 - 1 MOTHER'S FAMILY SIZE PLANS BY FATHER'S FAMILY SIZE PLANS

		Mother				
		No effect	No more children	Must have another	Other	Total
Father	No effect	59	9	0	3	71
	No more children	3	22	1	0	26
	Must have another	1	3	4	0	8
	Not known	24	9	0	6	39
	Total	87	43	5	9	144

P = less than .001 X^2 = 114.7791

Table 73 - 1 demonstrates the high correlation between fathers and mothers in respect of their family size plans; only 17 families of the 106 in which evidence was available from both parents showed any conflict of opinion or decision. It would appear that this is not a major area of marital stress.

Differing Opinions on Family Size Plans

Father	Total	Mother
No effect	9	No more
No more	3	No effect
No more	1	Want another
Want another	3	No more
Want another	1	No effect
Total	17	

74. Effect on time spent at home by Father	No.	Per cent.
No change	67	46.5
Less time	6	4.2
More time	32	22.2
Not known	39	27.1

75. Reason for any change in time spent at home by Father	No.	Per cent.
Because of handicapped child	20	13.9
Other reason/no change/Not known	124	86.1

Of the 38 fathers who reported that they spent more or less time at home 20 (52.6%) attributed this change to the presence of the handicapped child.

76. Change of job by Father	No.	Per cent.
No	60	41.7
Yes	47	32.6
Not known	37	25.7

77. Reason for change of job by Father	No.	Per cent.
Because of handicapped child	5	3.5
Other reason/not applicable/Not known	139	96.5

There was a great deal of job mobility recorded by the fathers, but only five moves were attributed to the demands made by the handicapped child. Two farm labourers/market gardeners moved to Edinburgh in order to obtain better facilities for (in each case) their multiply handicapped child; one miner moved from coal face to surface working in order to get regular hours at work and at home helping to control his hyperactive and destructive boy; one plumber gave up his own business to work shorter hours for an employer, and one long distance

lorry driver chose the lesser pay and the prospect of more time at home of local delivery work.

78. Change of hobbies/interests by the Father	No.	Per cent.
No	81	56.2
Yes	28	19.4
Other/Not known	35	24.3

79. Reason for change of hobbies/interest by Father	No.	Per cent.
Because of handicapped child	18	12.5
Other reason/no change/not known	126	87.5

The information we were seeking from these questions was how many fathers had, for instance, become involved in one of the voluntary societies, etc. One father whose child was in hospital, in his own words "Salved my conscience by becoming a member of the executive committee of a local branch of the SSMHC." For the most part, however, we listened to complains about abandoned golf, darts and soccer. In one home we registered a snort of derision from the wife of an unemployed man who had fathered ten children before the age of 30.

80. Effect on Mother's Family Size Plans	No.	Per cent.
No effect	87	60.4
No more children	43	29.9
Must have another to make up	5	3.5
Other (sterilised, 7: widows, 2)	9	6.2

We did not ascertain whether sterilisation had in every case been precipitated by the birth of the handicapped child, though three mothers volunteered this information.

In the first group of mothers were the following:-

"I could never say 'No' but I'm awfully frightened."

"I wouldn't mind even though I am 45."

"I wouldn't mind another one, but with having K you couldn't give them both attention. One would have to go without. K's so jealous."

"My last pregnancy was nine months of terror."

Those who had definitely decided to have no more children expressed comments in this vein:-

"At our age?! If I had another pregnancy I would ask for termination because once you've had one Mongol you're more likely to have another."

"I don't want any more. I didn't want him."

"I was told there was a 20:1 chance of a repeat. I thought the odds were too high."

A great deal of blaming self, partner or the medical profession was articulated at this point. One mother complained bitterly:-

"I wanted an abortion when I knew I was pregnant. They refused me, saying my heart was strong enough and I'd have a healthy child....."

Had some of the information yielded by this question been to hand when we scored parents' initial reactions, that picture might have been different. However, we feel that more justice is done to the material by presenting it in the order it was expressed, than by imposing a retrospective order. Parental insights and outbursts, as evidenced in a sample of the verbatims, indicate the shifting pressures as the interview proceeded and the difficulty of establishing a constant base line in attitudinal studies.

TABLE 80 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY MOTHER'S FAMILY SIZE PLANS

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No effect	48	33	6	87
No more children	8	21	14	43
Other	5	5	4	14
Total	61	59	24	144

P = less than .01 X^2 = 22.8741

Whereas the majority of mothers (78.6%) who do not see the child as mentally handicapped claim no effect on family size plans, 58% of mothers assessing the child as severely handicapped intend to have no further children (Table 80 - 1).

TABLE 80 - 2 SOCIAL CLASS BY MOTHER'S FAMILY SIZE PLANS

	I - II	III	IV - V & Other	Total
No effect	13	33	41	87
No more children	9	19	15	43
Other	2	3	9	14
Total	24	55	65	144

P = less than .05 X^2 = 11.0644

Maternal family size plans show a correlation with social class; 39% of Classes I - II mothers plan no further children as opposed to 23% of Classes IV, V and Other mothers (Table 80 - 2).

TABLE 80 - 3 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY MOTHER'S FAMILY SIZE PLANS

	More handicapped	Less handicapped	Not tested	Total
No effect	31	39	17	87
No more children	15	12	16	43
Other	8	4	2	14
Total	54	55	35	144

P = N.S. $X^2 = 8.4695$

Although the differences are not significant, over one third (37.2%) of the mothers who decided to have no more children have a child who has not been assessed by the psychologist (Table 80 - 3).

81. Effect on Mother's Social Life	No.	Per cent.
No effect	94	65.3
Less social life	50	34.7

82. Reason for change in Mother's Social Life	No.	Per cent.
Because of handicapped child	45	31.2
Other reason/No change in social life	99	68.7

Five mothers of the 50 with less social life attributed this to the demands of all the children, but 45 claimed that the handicapped child created strains and imposed limitations greater than and for a longer period than his siblings.

This is how a selection of the mothers replied:-

"The older boys are always out, and we would be if we could. It bites when you consider what your life is compared with what it could be. But the future is brighter than the past."

"I'll not leave him with any one. I've got to know that they know him."

"We can't go out as a family unit to places which would be of interest to other members of the family, e.g. cinema, theatre, museum, etc. We do things by separation rather than together, perhaps."

"Things take longer. We go out less often to fewer places."

"You lost your pals. The difficulty of answering questions about how the baby was getting on ... it was even worse if they didn't know."

TABLE 81 - 1 MOTHER'S RELATIONSHIP TO CHILD BY EFFECT OF MOTHER'S SOCIAL LIFE

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No effect	17	18	59	94
Less social life	13	17	20	50
Total	30	35	79	144

P = less than .05 X^2 = 7.0259

TABLE 82 - 1 MOTHER'S RELATIONSHIP TO CHILD BY REASON FOR CHANGE IN MOTHER'S SOCIAL LIFE

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Because of handicapped child	11	17	17	45
Other reason/No change	19	18	62	99
Total	30	35	79	144

P = less than .02 X^2 = 8.7788

Tables 81 - 1 and 82 - 1 show that half the ambivalent mothers said they had less social life and in every case they attributed this to the presence of the handicapped child.

TABLE 81 - 2 ORDINAL POSITION OF CHILD BY EFFECT ON MOTHER'S SOCIAL LIFE

	Oldest/Only	Youngest	Middle	Total
No effect	23	35	36	94
Less social life	10	31	9	50
Total	33	66	45	144

P = less than .02 X^2 = 8.9552

TABLE 82 - 2 ORDINAL POSITION OF CHILD BY REASON FOR CHANGE IN MOTHER'S SOCIAL LIFE

	Oldest/Only	Youngest	Middle	Total
Because of handicapped child	7	29	9	45
Other reason/No change	26	37	36	99
Total	33	66	45	144

P = less than .02 X^2 = 9.1446

The effect on mother's social life is then examined by the ordinal position of the child; perhaps not surprisingly, the greatest effect was reported when the handicapped child was the youngest (Table 81 - 2) and 29 out of 66 mothers of youngest children (43.9%) attributed the reduction in social life to the handicapped child (Table 82 - 2).

TABLE 81 - 3 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY EFFECT ON MOTHER'S SOCIAL LIFE

	More handicapped	Less handicapped	Not tested	Total
No effect	30	43	21	94
Less social life	24	12	14	50
Total	54	55	35	144

P = less than .05 X^2 = 6.7219

TABLE 82 - 3 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY REASON FOR CHANGE IN MOTHER'S SOCIAL LIFE

	More handicapped	Less handicapped	Not tested	Total
Because of handicapped child	21	8	16	45
Other reason/No change	33	47	19	99
Total	54	55	35	144

P = less than .01 X^2 = 12.0174

Tables 81 - 3 and 82 - 3 analyse the changes in mother's social life by the psychologists assessment of degree of handicap; 39% of the mothers with more handicapped children attributed the reduction in social life to the presence of the handicapped child, but this was true of only 15% of the mothers with less handicapped children.

SECTION V DATA ON COPING, HOPES AND FEARS FOR THE FUTURE

83. Parents' Assessment of Ability to Cope	No.	Per cent.
Not well with stress	5	3.5
Not well without stress	3	2.1
Well with stress	56	38.9
Well without stress	80	55.6

The category of coping not well without stress would seem contradictory, but was included in the hopes of identifying families who sensed their incompetence but were unperturbed by it. In the event there were only three families in this category (the same families assessed themselves and were assessed by the interviewers). From the sample of verbatims listed below it can be seen how difficult it was to score the parents on their own testimony, for there were manifest contradictions and tacit over-compensations:-

"I'm O.K. until after visits to see him in Gogarburn Hospital, then I'm upset."

"We're coping fine. We bring him up as a normal child, he gets discipline and encouragement. We wouldn't part with him - it would be like losing the sunshine out of our lives."

"It would give parents of new born Mongol children a big lift to show them H and say, 'Here's what you can do with a Mongol'."

"H is beginning to respond to my anxiety and upset. I wish I could control it till she's in bed."

"All right. If you don't get on today you'll get on tomorrow."

"I feel at times its going to explode and I want to run away."

"I think we should get an O.B.E. or something."

"F: Just about. My wife's on heavy sedation. M: Some days I don't cope and the next day work twice as hard to make up. As a stepmother I feel guilty because I'm not giving the other two what they need."
"F: Not too bad. M: We check each other if one of us gets lenient."
"At times she gets on your nerves. You get all your housework done and then M comes along and spoils it."
"He's just the same as the rest of them. No different, except that he never gets hit - you haven't the heart to."
"I don't think you can ever feel you do enough, and at the same time you know you're doing the best you can."
"F: We're doing our best but finding it hard. M: You've just got to cope, but some days I could scream. You can't feel the same towards him as the others."

TABLE 83 - 1 MOTHER'S RELATIONSHIP TO CHILD BY PARENTS' ASSESSMENT OF ABILITY TO COPE

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Not well/Well + stress	14	26	24	64
Well - stress	16	9	55	80
Total	30	35	79	144

P = less than .01 $X^2 = 19.0115$

Three quarters of mothers (74%) judged to be ambivalent or rejecting in attitude assessed their families as coping not well or well with stress. It must be recognised that this table can give no indication which of these (the poor coping or the ambivalent attitude) came first in time (Table 83 - 1).

TABLE 83 - 2 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY PARENTS' ASSESSMENT OF ABILITY TO COPE

		Interviewers			
		Not well ± stress	Well + stress	Well - stress	Total
Parents	Not well ± stress	7	1	0	8
	Well + stress	5	49	2	56
	Well - stress	2	27	51	80
	Total	14	77	53	144

P = less than .01 X^2 = 110.0986

In Table 83 - 2 the parents' assessment of coping ability is analysed by the interviewers' assessment of parental coping ability; the major difference relates to the parents' assessment, 'Coping well without stress'. Of the 80 in this category, the interviewers re-classified 27 as coping well with stress, and two as coping not well.

84. Interviewers' Assessment of Parental Coping Ability	No.	Per cent.
Not well with stress	11	7.6
Not well without stress	3	2.1
Well with stress	77	53.5
Well without stress	53	36.8

As with the interviewers' judgment on the father's and mother's relationship to the child (Questions 47 and 48), we based our scoring on verbatims, behaviour observed and emotional atmosphere absorbed. Again, much time was spent by the interviewers comparing their scores on this answer within a week of the interview before reaching a consensus.

TABLE 84 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Not well/Well + stress	32	38	21	91
Well - stress	29	21	3	53
Total	61	59	24	144

P = less than .02 X^2 = 9.1549

Seven out of eight (87.5%) of the parents who assessed their child as severely handicapped were placed by the interviewers in the coping not well or well with stress categories (Table 84 - 1).

TABLE 84 - 2 MOTHER'S RELATIONSHIP TO CHILD BY INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Not well/Well + stress	21	31	39	91
Well - stress	9	4	40	53
Total	30	35	79	144

P = less than .01 X^2 = 16.7814

Whereas 88.5% of ambivalent mothers and 70% of protective mothers were assessed by the interviewers as coping not well or well with stress, 50.6% of accepting mothers were considered to be coping well without stress (Table 84 - 2).

TABLE 84 - 3 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY

	More handicapped	Less handicapped	Not tested	Total
Not well/Well + stress	41	26	24	91
Well - stress	13	29	11	53
Total	54	55	35	144

P = less than .01 X^2 = 10.1923

When the interviewers' assessment of parental coping ability is analysed by the psychologist's assessment of degree of mental handicap, 75.9% of families with a more handicapped child were considered to be coping not well or well with stress (Table 84 - 3).

85. Best Help for Parents now			No.	Per cent.
Holiday admission	(5)	Relief of child		
Hospital admission	(2)	away from the		
Residential school	(6)	home	13	9.1
Genetic counselling	(5)	Improved help		
Counselling/Support	(34)	to cope at home	39	27.1
Different School	(13)	Educational		
Speech Therapy	(24)	betterment	37	25.7
Nothing/Not known			55	38.2

Amongst the parents in the first broad category were these:-

"M: I'd like a five day residential school. F: I don't like them en masse, they can't compete with one another. There's no race for them to run, no standard to achieve."

"M: I'd like him in a residential school for a few months to see how he got on."

"The school at X is nearly ready now. Home for weekends; but I'd like the freedom during the week."

"I think every person with a child like this could do with a holiday free from the child. I'd like to see him boarded at a school for a while."

"An occasional weekend on our own."

"You shouldn't need to be at last gasp before you get him into Gogarburn. You shouldn't need to degrade yourself and tell lies to get him in. He would be better there, wouldn't come to any harm. I know its a narrow margin before one of us has a breakdown. We're assumed to be coping adequately because of our life-style."

Parents wanting more (genetic) counselling or support remarked:-

"We should have had more genetic counselling after the first child, an epileptic, was born. Instead, I had a miscarriage, then R (a Mongol). If I'd known I wouldn't have gone on. Now I'm sterilised but its too late."

"Another mother for him, two pairs of eyes and hands, somebody beside you all the time. Its a full time job to contend with him."

"There should be a clinic for mentally handicapped children, but it should be someone human at the other end. It would save bothering your own G.P. and most Health Visitors are not trained for them; they're as much at sea as I am. Advice is needed."

"We need more information on progress at school, job prospects, and suitable accommodation when we've gone."

"We wish we could have a baby-sitter as a special service. You can't leave him with just anyone. Being on the 'phone gives us an easier mind, but we do wish there could be special sitters."

"I would like a place where you could go and ask a professional if you're doing the right thing."

"I feel I could do with more advice on how to handle her."

Parents seeking some form of educational betterment commented:-

"Speech therapy."

"Putting him back at ordinary school. The others at the school are overworked and he gets neglected. We want to help him with his home-work at home, but the teachers don't co-operate."

"If I could get K into nursery it would help. (To child on her lap) 'It would help you, too, wouldn't it, to play with all those children?' She won't even go near my husband."

"'Stream' the special class children more by ages instead of lumping them altogether. When the teacher is teaching the 5 year olds the 12 year olds are past it."

"Speech therapy. She's bright enough and physically fit. It only needs her speech improving."

"A different school for him and help for us. I wouldnae like to see him going to hospital away from us. Rather, help for us to keep him at home. We've struggled for seven years. Where there's a will there's a way. He needs to learn the fundamentals, what's right and what's wrong."

Two specific requests which were impossible to classify within any of the condensed tables were:-

"An oxygen bottle and mask at home for when H has one of her turns. She has an inoperable hole in the heart and cyanoses easily."

"Extending the garden fence to keep him off the busy main road."

We will comment on the extraordinary insistence on and fantasies surrounding speech therapy under Question 86. Within three months of our interviews ending two children whose parents we had interviewed had been admitted to Gogarburn Hospital.

TABLE 85 - 1 PARENTS' ASSESSMENT OF ABILITY TO COPE BY BEST HELP FOR PARENTS NOW

	Not well ± stress Well + stress	Well - stress	Total
Child away from home	9	4	13
Counselling/Support	24	15	39
Educational betterment	14	23	37
Nothing/Not known	17	38	55
Total	64	80	144

P = less than .01 X^2 = 12.5841

When the parents' requests for help were analysed by their assessment of how they were coping, 37.5% of parents feeling themselves to be coping not well or well with stress listed counselling/support as their main need, whilst 69% of parents who had no special needs or did not know were judged by themselves to be coping well without stress (Table 85 - 1).

TABLE 85 - 2 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY BEST HELP FOR PARENTS NOW

	Not well ± stress	Well + stress	Well - stress	Total
Child away from home	5	6	2	13
Counselling/Support	4	29	6	39
Educational betterment	3	16	18	37
Nothing/Not known	2	26	27	55
Total	14	77	53	144

P = less than .01 X^2 = 27.8301

Table 85 - 2, interviewers' assessment of parental coping ability by best help for parents now, shows that 77 parents considered to be coping well with stress included 29 (37%) who asked for counselling/ support. This correlates well with the parents' estimate given in the previous table.

86. Target in Child's Education	No.	Per cent.
Day Centre	14	9.7
Junior Occupation Centre	19	13.2
Special School/Class	56	38.9
Ordinary School	33	22.9
None envisaged	9	6.2
Not known	13	9.1

Parents had measurably more to say about the child's present and future education than any other item in the entire interview. There is no doubt that parents overwhelmingly 'see' mental handicap as an educational problem, or as a condition best ameliorated by educational intervention; yet their informants and supporters (if any) are initially if not predominantly medical personnel. The transference in parents' attention from the doctors to the teachers is quite noticeable. The first have proved largely unsuccessful in 'curing' or 'changing' the child's mental handicap, the latter, surely, can only improve on the doctors' record by developing the child's ability to learn, already demonstrated in the parents' success in teaching him toilet-training, social skills and manners, and so on.

We cite a small sample of verbatims, in ascending order of educational ambition:-

"Can a child of zero have an educational target?"

"Nothing definable. It looks like being a short life, and I'd like it to be comfortable for him."

"They've told us he's subeducable. If he can be taught to read and recognise simple things, appreciate his surroundings, I'll be content."

"We hope a J.O.C., but just now that's a long way off. M: He's come on so well in the last six months anything might happen."

"The tendency in J.O.C's is to occupy their time, but not their minds. She needs to be independent, recognise her potential. They should begin earlier with mentally handicapped children. There are too few places. Her progress is dependent on the places available rather than on her ability. Parents need more contact with the school. The proposed Parent-Teacher Association was rejected out of hand. We could even help the school by exerting pressure on the Local Authority, local councillors, etc."

"We're really pleased with the J.O.C. Twelve kids, two teachers genuinely interested in children. We would like to see her receiving some formal education, though we don't expect academic qualifications."

"No target. We look for the worst and hope for the best."

"She passed tests enough to go to ordinary school but I preferred her to go to special school. She needs the extra attention. I'm not ashamed of the school. The classes are smaller."

"We think deep down that she could break through. We want the chance to help her on, even if it takes time, effort and devotion. We hope she will go to ordinary school, even if at the bottom of her class."

"I don't know. If her speech could be improved I don't see why she shouldn't go to ordinary school."

"She could go to ordinary school if only her speaking would improve.

F: She's not right for normal school."

"F: I'd like to see him at an ordinary school. M: A change of schools wouldn't do any good."

"These special schools are all very well, but I would prefer a special class in an ordinary school. It would be much better than segregating children. There would be less cruelty by the able towards the less able if children were brought up together."

"I wouldnae want him to go to normal school; the others would be cruel. To me, he's a Mongol. It doesnae matter how clever or daft he is, he'll never amount to much."

TABLE 86 - 1 PRESENT PLACEMENT OF CHILD IN EDUCATIONAL SYSTEM BY PARENTS' FUTURE EDUCATIONAL TARGET FOR CHILD

		Present Placement of Child			
		Day Centre	J.O.C.	Special School/Class	Total
Future Target for Child	Day Centre	10	0	0	10
	J.O.C.	5	13	0	18
	Special School/ Class	0	15	22	37
	Ordinary school	0	5	24	29
	Not known	1	0	2	3
	Total	16	33	48	97

Excluded from this table are eight children now at home, nine children now in Gogarburn Hospital and 30 children now in playgroup or nursery school.

P = less than .01 $\quad X^2 = 91.2116$

Table 86 - 1 analyses the present placement of children already in the educational system by the parents' target for his education; almost

half the parents (47.8%) with a child now in Special School/Class fully expect him to catch up and be transferred to an ordinary school, whilst of the 33 parents with a child now in J.O.C. 45% expect the child to progress to a Special School/Class, and 15% predict his eventual transfer to an ordinary school. The hopes of 60.7% of parents with a child now in J.O.C. are pinned entirely on speech therapy, seen as the key to unlock all doors. As the average age of the children in our sample was 6 years 4 months it must remain conjecture how long such parental hopes can be sustained. More counselling for parents as well as more speech therapists could make clearer the benefits and limits of speech therapy.

TABLE 86 - 2 SOCIAL CLASS BY TARGET IN CHILD'S EDUCATION

	I - II	III	IV - V & Other	Total
Day Centre	1	7	6	14
J.O.C. then S.T.C.	7	5	7	19
Special School/ Class	10	23	23	56
Ordinary school	3	14	16	33
None envisaged (9) Not known (13)	3	6	13	22
Total	24	55	65	144

P = less than .02 X^2 = 19.5917

In Table 86 - 2 the parents' educational target for the child is analysed by social class. The most striking finding is that of the parents who envisage their child in an ordinary school, eventually, only 9.1% are in Classes I - II, whilst 50% are in Classes IV, V and Other. This can either be interpreted as proof of the greater

reality-testing skills of professional class parents, or as atypical evidence that some lower class families, at least, do cherish values and pursue goals such as educational achievement, normally reckoned to be outwith their concern.

TABLE 86 - 3 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY TARGET IN CHILD'S EDUCATION

	More handicapped	Less handicapped	Not tested	Total
Day Centre	9	4	1	14
J.O.C. then S.T.C.	18	0	1	19
Special School/ Class	7	24	25	56
Ordinary school	8	22	3	33
None envisaged (9) Not known (13)	12	5	5	22
Total	54	55	35	144

P = less than .01 X^2 = 50.2968

Table 86 - 3 analyses the parents' future educational target for the child by the psychologist's assessment of degree of mental handicap; the majority of parents whose child had not been tested (71.4%) believe he will go to Special School/Class, whereas 28% of parents whose child has been assessed as more handicapped imagine the child will progress to Special School/Class.

TABLE 86 - 4 DEGREE OF MENTAL HANDICAP OF CHILD BY TARGET IN CHILD'S EDUCATION

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Day Centre	3	4	7	14
JOC then STC	4	11	4	19
Special School/ Class	25	27	4	56
Ordinary school	23	10	0	33
None envisaged (9) Not known (13)	6	7	9	22
Total	61	59	24	144

P = less than .01 X^2 = 25.5294

As if to underline the reasonableness of their answer to Question 18, 'I do not think or am not sure that he is mentally handicapped in comparison with other children,' the parents' assessment of degree of mental handicap and future educational target show a very close 'fit' (Table 86 - 4). Of those with a child in the 'Don't know/ Not sure' category, 78% envisage him in Special School/Class or ordinary school, whilst that ambition is true of only 62% of parents assessing 'some mental handicap' in their child, and in a mere - or perhaps surprising - 16% of parents assessing their child as 'severely mentally handicapped.'

87. Eventual Employment Prospects of Child	No.	Per cent.
Nothing (child now in hospital 9) (child now at home 13)	22	15.3
Not known	61	42.4
Industrial Therapy Unit (attached to Hospital) Senior Training Centre (L.A. Community centre)	12	8.3
Sheltered Workshop (run by Voluntary Society or Government sponsored)	10	6.9
Classes IV - V employment	30	20.8
Class III employment	3	2.1
Classes I - II employment	6	4.2

The high percentage of 'Don't knows' can probably be explained by the fact that the average age of the children was 6 years 4 months and work prospects cannot have loomed large in the minds of most parents. By adding the 22 who envisage the child (when adult) doing nothing to the 22 who opted for I.T.U., S.T.C. or Sheltered Workshop as a setting for their offspring, a total of 30.6% of parents are effectively declaring a realistic estimate of the severity of his mental handicap; a significantly higher percentage than was evident in the previous question. Their short-term hopes for educational betterment were not sustained (in this interview) to embrace his employment opportunities.

In their own words, this is how representative parents viewed his employment prospects:-

"Just sitting. He'll always need to be looked after."

"We're reconciled to that. We think how dreadful it must have been in the Dark Ages." (Child now in Gogarburn Hospital)

"He's good with his hands. Mostly they end up in Rehabilitation Centres. I'd rather he got a job in a factory outside."

"Something to bring him a little satisfaction. Errand boy or animal feeder at the zoo."

"Whatever he's capable of - unless its stealing. Either a surveyor or a farmer or whatever he's happy at."

"When he gets older I'd like him to stay at home. I feel if he worked with others they might take advantage of him."

"Maybe I could get a small shop and let my wife run it with C to help her."

"He'll either be in and out prison or he'll drink."

"If everything goes according to plan he's going to be a doctor."

"According to his bone structure he'll be four foot six - make a great jockey."

"I'm saving up his Special Attendance Allowance and putting it by. It might help him to set up as a gardener and work with flowers. Not to make money but to occupy himself."

"It's surprising the things they can even learn monkeys to do. A repetitive job in a factory."

"A nurse."

"Receptionist in a hotel, typing, simple 'phone work."

"Maybe get a job with the demolition squad!"

TABLE 87 - 1 SOCIAL CLASS BY EMPLOYMENT PROSPECTS OF CHILD

	I - II	III	IV - V & Other	Total
Sheltered employment	5	8	9	22
Class IV - V	3	16	11	30
Class I - III	4	1	4	9
Nothing (22) Not known (61)	12	30	41	83
Total	24	55	65	144

P = less than .02 X^2 = 15.7799

Parents, by and large, expect even their handicapped child to follow in his father's footsteps as the social class analysis shows (Table 87 - 1). Class III parents significantly saw a substantial falling back from their position; in only one case was it thought likely that their child would equal or better his father's status. Classes IV, V and Other parents reckoned on their children emulating the fathers in 16% of cases, and 6% anticipating the children rising to skilled manual or professional status. The fact that 42.4% did not know what he might achieve, however, is the most realistic fact in this answer.

TABLE 87 - 2 SEX OF CHILD BY EMPLOYMENT PROSPECTS OF CHILD

	Male	Female	Total
Sheltered employment	15	7	22
Class IV - V	25	5	30
Class I - III	8	1	9
Nothing (22) Not known (61)	48	29	83
Total	96	48	144

P = greater than .05 $X^2 = 6.1921$

Table 87 - 2, sex of child by eventual employment prospects shows that only 30.2% of the boys' parents could see him in open employment (which contrasts with the 76.4% of boys' parents who estimated earlier that he would go to special school or ordinary school). Six out of every ten parents of girls did not know what work she would undertake.

88. Attitude to Child's Eventual Marriage	No.	Per cent.
No	60	41.7
Yes	59	40.9
Disagreement between parents	6	4.2
Not known	19	13.2

This was a question we hesitated to ask in some homes with a profoundly handicapped child, especially where the parents had just written him off in terms of his education and employment prospects. However, we did ask it in every home and were surprised at the number of parents with a severely handicapped child who hoped he would marry. It represented either his one chance of doing something normal, or their one chance of being relieved of his lifelong guardianship. In this connection the parents of Mongol children were peculiarly perplexed; 28 were against marriage, six were for marriage and four disagreeing about its feasibility or desirability.

Those parents (not exclusively of Mongols) against marriage said:-

"I've often thought about it, but I've visions of him being with me all the time. He probably won't bother about girls."

"F: Can Mongols marry? I would stop it if I thought he would rear another Mongol. M: These children should be sterilised."

"F: J's a Mongol. Its out."

"M: I don't think he'll have the sense ever to get married."

Parents expressing themselves in favour of the child's eventual marriage included these:-

"If she can marry, O.K. But I wouldn't want anyone to be foolish to her."

"Definitely, yes. It would make her less dependent on us."

"I'd love him to get married so that someone could love him and take care of him."

"If he was in his right mind, yes. But not if he gets worse instead of better."

"If she was able to take care of herself, yes. It's nothing hereditary."

"He's normal enough; he could have a family."

Parents who disagreed included the following:-

"M: If I thought she was capable I'd be only too pleased. F: I don't want her to get married."

"M: No. F: It would depend on circumstances. He might be able to get married and have no family."

"F: I'd be hoping some day he would. M: (silently weeping)."

TABLE 88 - 1 SOCIAL CLASS BY ATTITUDE TO CHILD'S EVENTUAL MARRIAGE

	I - II	III	IV - V and Other	Total
No	14	21	25	60
Yes	7	26	26	59
Disagree (6) Not known (19)	3	8	14	25
Total	24	55	65	144

P = less than .02 X^2 = 12.4533

Analysed by social class, 58% of parents in Classes I - II thought their child would not get married, as against 38% of parents in Classes IV, V and Other. With the latter group comprising the subcultural end of the spectrum of mental handicap it follows that most of these parents would see little incongruity in their children getting married (Table 88-1).

TABLE 88 - 2 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY ATTITUDE TO CHILD'S EVENTUAL MARRIAGE

	More handicapped	Less handicapped	Not tested	Total
No	36	9	15	60
Yes	13	38	8	59
Disagree (6) Not known (19)	5	8	12	25
Total	54	55	35	144

P = less than .01 X^2 = 41.8107

Parents' attitude to the child's eventual marriage correlates with the psychologist's assessment of degree of mental handicap; 67% of parents with more handicapped children thought they would not get married whilst 69% of parents with less handicapped children thought they would get married (Table 88 - 2).

89. Best Help for Child now	No.	Per cent.
Better/more education	43	29.9
Speech therapy	24	16.7
Better/more medical care (including hospitalisation)	13	9.1
Friends, opportunity for play, etc.	9	6.2
Love and affection	11	7.6
Nothing specified (35) Not known (9)	44	30.5

In the event it proved difficult for parents to think of types of help different from those which were currently available. What would help him most was what would help them most. To this extent, need is indivisible and services should be integrated.

We have commented already (Question 86) on the clamour for speech therapy and the magical powers with which many parents invested it. Of those asking for speech therapy 87.5% were parents of Mongol children.

Other types of help specified include the following:-

"She cannae learn nothing. She needs more play-space."

"We would choose to have a new heart operation. We would take the risk."

"I would be prepared to pay for a private speech therapist, but I'm told there isn't one."

"Physiotherapy and/or a walking frame. The only exercises we give her are painful to her and to us."

"A roof over his head, someone to feed him and keep him dry. When they invent brain transplants we'll be happy."

"Love and - I don't know - patience to guide him and build up his self-confidence."

TABLE 89 - 1 SOCIAL CLASS BY BEST HELP FOR CHILD NOW

	I - II	III	IV - V & Other	Total
Better/more education	8	16	19	43
Speech therapy	6	9	9	24
Better/more medical care	2	5	6	13
Other/Not known	8	25	31	64
Total	24	55	65	144

P = less than .01 X^2 = 20.2062

Analysing the best help for the child now by social class, the familiar pattern reasserts itself in that nearly 50% of parents in Classes IV, V and Other have no clear idea of what is needed, whereas 33%

of parents in Classes I - II want more or better education, 25% want speech therapy and 8% want more or better medical care. Including speech therapy as an adjunct to better/more education, 84% of the specific help desired by the parents was educational in nature (Table 89 - 1).

TABLE 89 - 2 DEGREE OF MENTAL HANDICAP OF CHILD BY BEST HELP FOR CHILD NOW

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Better/more education	18	22	3	43
Speech therapy	13	8	3	24
Better/more medical care	6	1	6	13
Other/Not known	24	28	12	64
Total	61	59	24	144

P = less than .02 X^2 = 15.8807

That parents see the problem as best being solved or resolved by educational means is indicated in the analysis by parents' estimate of the degree of mental handicap. Half the 'Don't know/Not sure' parents and half the 'some mental handicap' parents want educational intervention, whereas only one quarter of the 'severe mental handicap' parents want this type of help (Table 89 - 2).

90. Problems at Present - Incontinence	No.	Per cent.
No	70	48.6
Wetting at night	33	22.9
Wetting by day and night	4	2.8
Soiling and wetting by day and night	37	25.7

The percentage of parents now (46.8%) who claim to have a completely continent child is lower than the percentage (56.2%) who claimed such a child in answer to Question 20. We attribute this to the growing trust placed in the interviewers or the growing honesty manifested by the parents as the interview progressed, or both. Since only nine children are in Gogarburn Hospital, 28 out of the 37 (75.6%) families with a doubly incontinent child are faced with extra laundry tasks and costs at home.

TABLE 90 - 1 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY PROBLEMS AT PRESENT - INCONTINENCE

	Not well ± stress Well + stress	Well - stress	Total
No	35	35	70
Day and night wetting	24	13	37
Day and night double incontinence	32	5	37
Total	91	53	144

P = less than .01 X^2 = 13.9133

The interviewers' assessment of parental coping ability shows that 60% of parents judged to be coping not well or well with stress had an incontinent child (Table 90 - 1).

TABLE 90 - 2 MOTHER'S FAMILY SIZE PLANS BY PROBLEMS AT PRESENT - INCONTINENCE

	No effect	No more children	Other	Total
No	50	17	3	70
Day and night wetting	24	8	5	37
Day and night double incontinence	13	18	6	37
Total	87	43	14	144

P = less than .01 X^2 = 15.6632

There seem to be implications in the child's incontinence for the mother's family size plans; 60% of the families where the mother has decided to have no more children had incontinent children (Table 90 - 2).

TABLE 90 - 3 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY PROBLEMS AT PRESENT - INCONTINENCE

	More handicapped	Less handicapped	Not tested	Total
No	23	39	8	70
Day and night wetting	16	10	11	37
Day and night double incontinence	15	6	16	37
Total	54	55	35	144

P = less than .01 X^2 = 23.0144

The psychologist's assessment showed a correlation between incontinence and greater handicap; 57% of the more handicapped children were incontinent (Table 90 - 3).

TABLE 90 - 4 MOTHER'S RELATIONSHIP TO CHILD BY PROBLEMS AT PRESENT - INCONTINENCE

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
No	13	6	51	70
Day and night wetting	6	17	14	37
Day and night double incontinence	11	12	14	37
Total	30	35	79	144

P = less than .01 X^2 = 25.2612

The emotional impact of incontinence on the mother's relationship to the child is suggested by the fact that 82% of ambivalent or rejecting mothers, as against 35% of accepting mothers, have incontinent children (Table 90 - 4).

TABLE 90 - 5 AGE OF CHILD BY PROBLEMS AT PRESENT - INCONTINENCE

	6 and over	4 - 5	Less than 4	Total
No	59	11	0	70
Day and night wetting	27	9	1	37
Day and night double incontinence	14	15	8	37
Total	100	35	9	144

P = less than .01 X^2 = 32.8549

This table, age of child by incontinence, demonstrates that incontinence is, for many children, partly age-related; 75% of children under 5 years old are incontinent and 59% of those aged 6 and over are not (Table 90 - 5).

TABLE 90 - 6 DEGREE OF MENTAL HANDICAP OF CHILD BY PROBLEMS AT PRESENT - INCONTINENCE

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	38	29	3	70
Day and night wetting	14	20	3	37
Day and night double incontinence	9	10	18	37
Total	61	59	24	144

P = less than .01 X^2 = 39.4465

The last table shows that degree of mental handicap estimated by the parents correlates with the presence or absence of incontinence; 21 out of 24 (89%) severely handicapped children were incontinent (Table 90 - 6).

91. Problems at Present - Overactivity	No.	Per cent.
No	62	43.1
Very active by day	59	40.9
Active night and day	16	11.1
Never stops for a moment	7	4.9

There is no means of pronouncing on the accuracy of parental grading of the child's overactvity, except that the seven 'non-stop' children were in a class apart, judged on their behaviour whilst we were in the home. Well over half the families claimed overactivity in the handicapped child as a definite problem.

TABLE 91 - 1 SOCIAL CLASS BY PROBLEMS AT PRESENT - OVERACTIVITY

	I - II	III	IV - V & Other	Total
No	11	26	25	62
Very active by day	11	20	28	59
Active night and day	2	9	12	23
Total	24	55	65	144

P = less than .05 X^2 = 11.0438

Social class distribution indicates that 77% of children in Classes IV, V and Other homes are overactive by day and by night, as compared with 50% of children from Classes I - II homes (Table 91 - 1). Possibly the larger families in working class homes provide more prolonged stimulation to an excitable handicapped child; conversely, the smaller families in professional class homes with one room per child afford opportunities for the child (and everyone else) to rest in quietness and seclusion.

TABLE 91 - 2 PARENTS' ASSESSMENT OF ABILITY TO COPE BY PROBLEMS AT PRESENT - OVERACTIVITY

	Not well ± stress Well + stress	Well - stress	Total
No	21	41	62
Very active by day	27	32	59
Active night and day	16	7	23
Total	64	80	144

P = less than .02 X^2 = 8.7269

Two thirds of parents with an overactive child in the home assessed themselves as coping not well or well with stress (Table 91 - 2).

TABLE 91 - 3 INTERVIEWERS' ASSESSMENT OF PARENTAL COPING ABILITY BY PROBLEMS AT PRESENT - OVERACTIVITY

	Not well ± stress Well + stress	Well - Stress	Total
No	35	27	62
Very active by day	38	21	59
Active night and day	18	5	23
Total	91	53	144

P = N.S. $X^2 = 3.4931$

The interviewers placed more than half (61.5%) the parents with an overactive child in the coping not well or well with stress category (Table 91 - 3). In neither of these tables (91 - 2 and 91 - 3), however, is the correlation as high as might have been expected; the parents may have overestimated their child's overactivity in the presence of sympathetic interviewers, or alternatively, overactivity may not be seen as so abnormal in families who cope well without stress.

92. Problems at Present - Eating Problems	No.	Per cent.
No	93	64.6
Eats very little	14	9.7
Has to be fed, feeds himself slowly and with difficulty, needs special utensils	37	25.7

One quarter of the families had children who - we presume - made mealtimes a lengthy business.

TABLE 92 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY PROBLEMS AT PRESENT - EATING PROBLEMS

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	48	40	5	93
Eats very little	4	9	1	14
Has to be fed, self-reliant with difficulty	9	10	18	37
Total	61	59	24	144

P = less than .01 X^2 = 39.6388

Parents clearly correlated eating problems with degree of mental handicap; 75% of those judged to be severely handicapped had eating problems compared with only 15% of those judged to be not handicapped (Table 92 - 1).

93. Problems at Present - Food Rituals/Obsessions	No.	Per cent.
No	140	97.2
Yes	4	2.8

One child ate no solids at all; one child ate only tinned baby foods (3,000 tins a year, the parents groaned); one child ate only fine strained food whilst sitting on his mother's lap, and one child ate compulsively and indiscriminately (Prader Willi syndrome). The first three are boys, the last a girl, all aged between 4 and 5 years.

94. Problems at Present - Sleeping Problems	No.	Per cent.
No	101	70.1
Poor sleeper	25	17.4
Interrupts parents most nights	18	12.5

One interesting finding was that over one third (34.8%) of the children with some sleeping problems were Mongols, nine classed by the parents as poor sleepers, six disturbed their parents most nights. The six in the last category spent at least part of every night in bed with their parents, to the undisguised indignation of the fathers in each case.

TABLE 94 - 1 SOCIAL CLASS BY PROBLEMS AT PRESENT - SLEEPING PROBLEMS

	I - II	III	IV - V & Other	Total
No	19	36	46	101
Poor sleeper	2	10	13	25
Interrupts parents most nights	3	9	6	18
Total	24	55	65	144

P = greater than .05 X^2 = 8.1801

There are no significant differences in social class in families with a child having sleeping problems (Table 94 - 1).

TABLE 94 - 2 PARENTS' ASSESSMENT OF ABILITY TO COPE BY PROBLEMS AT PRESENT - SLEEPING PROBLEMS

	Not well ± stress Well + stress	Well - stress	Total
No	35	66	101
Poor sleeper	15	10	25
Interrupts parents most nights	14	4	18
Total	64	80	144

P = less than .02 X^2 = 14.4710

Parents' assessment of ability to cope, not surprisingly, was correlated with a child who made demands on them by night as well

as by day; whilst only 17% of families with a child who slept poorly or interrupted the parents' sleep thought they were coping without stress, 45% of families with such a child thought they were coping well with stress or not well (Table 94 - 2).

95. Problems at Present - Rocking/Banging	No.	Per cent.
No	85	59.0
Yes	59	40.9

Whilst many parents claimed that their child was merely imitating others in his playgroup, nursery school, school bus or classroom, four in every ten parents had observed his tendency to rock (with or without the stimulus of music) and/or to hit himself or bang his head against the cot or wall.

TABLE 95 - 1 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY PROBLEMS AT PRESENT - ROCKING/BANGING

	More handicapped	Less handicapped	Not tested	Total
No	28	44	13	85
Yes	26	11	22	59
Total	54	55	35	144

P = less than .01 X^2 = 18.0826

Analysis of the child's tendency to rock/bang by the psychologist's assessment of degree of mental handicap suggests that parents were accurate in their reporting of this behaviour pattern; almost half (49%) the more handicapped children displayed this characteristic, as against one in five of the less handicapped (Table 95 - 1).

TABLE 95 - 2 SOCIAL CLASS BY PROBLEMS AT PRESENT - ROCKING/BANGING

	I - II	III	IV - V & Other	Total
No	19	36	30	85
Yes	5	19	35	59
Total	24	55	65	144

P = less than .01 X^2 = 14.8129

The rocking/banging tendency seems to be class related; it featured in 20.8% of Classes I - II families, 34.5% of Class III families and 53.8% of Classes IV, V and Other families (Table 95 - 2). This may indicate that professional class parents try harder to eradicate this habit from their child than other parents; or it may explain the comments made in many working class homes ("It keeps him happy", "It doesn't do any harm" and "It doesn't mean anything, does it?") namely, that these parents do not see it as a socially undesirable or medically diagnostic habit.

96. Problems at Present - Temper Tantrums	No.	Per cent.
No	83	57.6
Yes	61	42.4

We explained to parents that we were not concerned with the normal flashes of childish temper but with prolonged paroxysms or violent behaviour. In this light, no less than four in every ten parents admitted their child displayed such violent behaviour, and many gave graphic descriptions of the damage he inflicted on himself or anyone or anything within reach. When frustrated such children indulged in arm-biting, hair pulling, head banging on themselves and physical assault on siblings, parents, other children and adults.

TABLE 96 - 1 PARENTS' ASSESSMENT OF ABILITY TO COPE BY PRESENT PROBLEMS - TEMPER TANTRUMS

	Not well ± stress Well + stress	Well - stress	Total
No	28	55	83
Yes	36	25	61
Total	64	80	144

P = less than .01 X^2 = 8.1061

Of families having a child subject to temper tantrums 59% felt they were coping not well or well with stress, 41% therefore felt they were coping well without stress (Table 96 - 1).

97. Main Fear for the Future	No.	Per cent.
None specified 7 Not known 18	25	17.4
Not work	10	6.9
Not marry	2	1.4
Get into trouble (with the police)	6	4.2
Be got into trouble (easily led by others)	21	14.6
Parents dying first	54	37.5
Child not improving	26	18.1

The last three questions (97 - 99) made a fairly traumatic conclusion to the interview in most homes. The parents might have sensed that the interview was drawing to a close and felt free to express their anxiety, or they might have been distressed at being made, together and in the presence of strangers, to face what they would rather have left alone. Much heart-searching and in many homes open weeping, marked the close of the interview.

They articulated their fears in these typically representative ways:-

"Knowing he can't handle a job or lead men."

"I don't think I have one, she's so brilliant. Only that if she marries she gets a good husband."

"I'd be feared he got into trouble, his temper's that bad. His father laughs and makes him worse."

"He's going to end up a delinquent. He's definitely going to get into trouble. If he goes on the way he's going - if there's no improvement - I hope he dies before me."

"We're worried about trends re euthanasia and population control, etc. (Child in Gogarburn Hospital).

"I'm trying to keep her with me all the time, because people will take advantage of her."

"If men take advantage of her when she gets older."

"We would like to outlive him."

"Him outliving us."

"F: Dying and leaving him. M: If doctors weren't so bloody smart in saving them we wouldn't have these problems. I would never ask my sons to look after him. The doctors can have him back."

"The fact of him being left alone. Wouldn't want him in an institution. We hope he could be self-supporting, or that institutions by then won't be institutions."

"Just that maybe he'll be rejected. You wonder how cruel people can be taking the Mickey out of him."

"I'm terrified of her going through childbirth in case she fitted during it. I read of such a case where the mother died and the child lived."

"I'm worried that my children might marry and have a mentally handicapped child. It's a pity.. It's taken all the joy out of them having a baby. I sit and think about these things too much...."
"There's a hundred and one. She may not have friends. She's just a box of tricks the now. We wouldn't want her to be shunned. M: You'd hate to have a fat, unhappy loafing teenager."
"I'd be frightened he might be put away into a hospital. He will if he gets much bigger. Then he didn't know who I was; only I would have suffered. Now he does now. I couldn't leave him; we'd both suffer."

There is real and often realistic concern expressed here. Whereas the parents of boys feared they might get into trouble with the police, the parents of girls feared they might be got into trouble by men. The fears of parents whose child is now in Gogarburn are revealing; the dread of euthanasia is sometimes a thinly veiled wish for it, if those same parents' other comments are studied. There is, indeed, a preoccupation with death in over half the parents' replies. It could be argued that this represents an acceptable censoring of unacceptable impulses; i.e. their fear of what they might do to the child is expressed as fear of what might happen to him when they are gone. On the other hand, many parents were naturally concenned about the quality of care which would be given to their child once they had died. As one mother put it:-
"Apart from people who work with these children, nobody cares."

TABLE 97 - 1 SOCIAL CLASS BY PARENTS' MAIN FEAR FOR FUTURE

	I - II	III	IV - V & Other	Total
Not work/Not marry	1	6	5	12
Cause or get into trouble	5	7	15	27
Parents dying first	10	25	19	54
Other (26) Not known (25)	8	17	26	51
Total	24	55	65	144

P = less than .05 X^2 = 13.2328

Analysed by social class, 41% of parents in Classes I - II and 45% of parents in Class III were worried at the prospects of dying first, a concern shared only by 29% of parents in Classes IV, V and Other. This group of parents in the main foresaw the major problem to be one of delinquent behaviour (Table 97 - 1).

TABLE 97 - 2 PARENTS' ASSESSMENT OF ABILITY TO COPE BY PARENTS' MAIN FEAR FOR FUTURE

	Not well ± stress Well + stress	Well - stress	Total
Not work/Not marry	5	7	12
Cause or get into trouble	19	8	27
Parents dying first	21	33	54
Other (26) Not known (25)	19	32	52
Total	64	80	144

P = less than .05 X^2 = 9.1295

Analysed by parents' assessment of ability to cope, causing or getting into trouble represented the second highest stress factor in those families who felt they were coping not well or well with stress (Table 97 - 2).

98. Concern for Child when Parents are dead	No.	Per cent.
No	35	24.3
Yes	109	75.7

99. Locus of Child when Parents are dead	No.	Per cent.
Independently or with relatives	63	43.7
Sheltered housing	2	1.4
Village for handicapped children	3	2.1
Group home	5	3.5
Hostel	8	5.6
Hospital	25	17.4
Not known	38	26.4

Together with his educational, employment and marital prospects, answers to this question disclosed the most conflict between the spouses' views. By and large the differences centred on the responsibility of his siblings to provide a home for the handicapped person. The following comments are fairly representative:-

"F: If the Lord takes us first, probably one of the boys. M: I wouldn't like to put them through what we've been through. F: It's good for character."

"She's got seven sisters and two brothers. I hope they wouldn't turn their back on her."

"We have her covered for one thousand pounds. We want one of her four sisters to take her."

"M: That's a dread. I wouldnae fancy an institution. F: I would like his sisters to ... M: No, that's not fair. F: No, I mean take an interest in him."

"Say 'His own wife.'"

"F: Not into an institution if possible. The family wouldn't see us stuck. M: (who had sat silent and tearful through the last part of the interview suddenly blurted out) Why does it happen to you? Why does anything happen?"

"Whichever of her sisters takes her on gets the house, too."

"I wouldn't like to burden F, spoil her life. Not a hospital but a village type community."

"Something like the school he goes to, only a permanent thing."

"I would like him to stay with someone who loves Mongol childs."

"With folks like hisself."

"M: A residential rather than a punitive atmosphere. Somewhere with a house mother. F: If I had the money I would put him away at a boarding school with no compunction. We would like him to get experience of other places, settings.. it gets him used to other people... so that the transition would not be too abrupt."

"The SSMHC are talking about these hostels they're building."

"She's the only one I do worry about. H won't stay with anyone but me and her dad. Because you're from Gogarburn it doesn't mean H is going to be taken there, does it?"

TABLE 98 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY CONCERN FOR CHILD WHEN PARENTS ARE DEAD

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
No	23	8	4	35
Yes	38	51	20	109
Total	61	59	24	144

P = less than .01 X^2 = 10.4167

TABLE 99 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY LOCUS OF CHILD WHEN PARENTS ARE DEAD

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Independently or with relatives	33	28	2	63
Group home, hostel, village, etc.	4	9	5	18
Hospital	1	10	14	25
Not known	23	12	3	38
Total	61	59	24	144

P = less than .01 X^2 = 49.4041

Tables 98 - 1 and 99 - 1 analyse parents' concern for the child on their death and where they would like him to live then by their own estimate of his degree of mental handicap; 87% of those who thought he had 'some mental handicap' and 80% of those who thought he had 'severe mental handicap' were concerned about his fate when they died. One third of those estimating 'some handicap' envisaged him living in either hostel or hospital accommodation, as did four out of five (78%) of those estimating 'severe handicap'.

TABLE 98 - 2 AGE OF CHILD BY CONCERN FOR CHILD WHEN PARENTS ARE DEAD

	6 and over	Less than 6	Total
No	27	8	35
Yes	73	36	109
Total	100	44	144

P = N.S. X^2 = 0.8564

TABLE 99 - 2 AGE OF CHILD BY LOCUS OF CHILD WHEN PARENTS ARE DEAD

	6 and over	Less than 6	Total
Independently or with relatives	49	14	63
Group home, hostel, village, etc.	14	4	18
Hospital	10	15	25
Not known	27	11	38
Total	100	44	144

P = less than .01 X^2 = 12.9113

There is no significance in the parents' concern when the age of the child is concerned (Table 98 - 2) but significantly 60% of those who want their child hospitalised after their own death have a child presently under 6 years old (Table 99 - 2). It is among parents of younger children that more of the severely handicapped are found and presumably many such parents know mainly or only of the hospital as a suitable residential placement.

The interview schedule as administered to the parents is covered by Questions 1 - 99. To the nearest five minutes the average interview lasted 70 minutes, the shortest 40, the longest 130 minutes. Questions 100 - 102 cast light on three subgroups within the total population sampled, namely single-parent families, Mongols and handicapped only sons. Question 103, the psychologist's assessment of the child's proposed educational placement, was given to the interviewers some time after the last interview had been completed.

100. Marital Status	No.	Per cent.
Married or re-married	126	87.5
Common-law marriages	2	1.4
Foster parents (1) Adoptive parents (1)	2	1.4
Widows	2	1.4
Separated or divorced wives	12	8.3

The numbers are small and we can do no more than describe the situation of particular families. The adoptive and foster parents had in each case made a home for a mentally handicapped girl. One widow had a handicapped boy, the other a handicapped girl. Ten of the separated or divorced wives had a handicapped boy; eight of them felt they were not coping well or well with stress; nine of them were judged by the interviewers to be coping not well or well with stress; in three cases the handicapped child was the only son; eight of these mothers were not receiving any counselling/support at present, two being helped by teachers and two by Voluntary Societies. We would suggest that single-parent families with a mentally handicapped child represent an 'At risk' group within the population of parents with mentally handicapped children. Within our sample, also, the presence of a handicapped boy seems more disruptive in a marriage than a handicapped girl; we cannot, however, make this a causal relationship without far more data than our survey yielded.

101. Handicapped Child is a Mongol	No.	Per cent.
No	106	73.6
Yes	38	26.4

As noted under Question 18, this is the only diagnosis reported by the parents which we accepted unequivocally. Mongols featured in a quarter of the families we interviewed, thereby warranting further

consideration. Already comments about this group of children and their families have been made; Table 39 - 5, doubly dissatisfied with the diagnostic interview; Questions 53 - 54, involvement with the Scottish Society for Mentally Handicapped Children; Questions 57 - 58, disappointment with counselling/support in the past; Question 71, complaints about dental care; Question 88, confusion over the child's eventual marriage; Question 89, magical properties invested in speech therapy as a cure-all, and Question 94, poor sleepers and disturbers of parents' sleep.

TABLE 101 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY CHILD IS MONGOL

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Mongol	5	30	3	38
All others	56	29	21	106
Total	61	59	24	144

P = less than .01 X^2 = 30.9455

Analysed by degree of mental handicap assessed by the parents, 13% of parents with Mongols thought their child was not handicapped or were not sure, and only 7% thought he was severely handicapped (Table 101 - 1).

TABLE 101 - 2 PSYCHOLOGIST'S ASSESSMENT OF CHILD'S EDUCATIONAL PLACEMENT BY CHILD IS MONGOL

	More handicapped	Less handicapped	Not tested	Total
Mongol	24	3	11	38
All others	30	52	24	106
Total	54	55	35	144

P = less than .01 X^2 = 21.9279

In comparison with the parents' optimistic estimates, the psychologist assessed 71% of the Mongol children they had seen as being more handicapped, recommending placement in a Day Centre of Junior Occupation Centre (Table 101 - 2).

TABLE 101 - 3 HANDEDNESS OF CHILD BY CHILD IS MONGOL

	Left/Both handed	Right handed	Total
Mongol	23	15	38
All others	34	67	101
Total	57	82	139

Excluded are the five Gogarburn Hospital children with "no grip"

P = less than .01 X^2 = 7.1632

Almost two thirds of the Mongol children (65%) were left or both handed (Table 101 - 3).

TABLE 101 - 4 ORDINAL POSITION OF CHILD BY CHILD IS MONGOL

	Oldest/Only	Youngest	Middle	Total
Mongol	8	24	6	38
All others	25	42	39	106
Total	33	66	45	144

P = less than .05 X^2 = 7.4067

Mongol children were over-represented in the 'Youngest' child group (Table 101 - 4).

TABLE 101 - 5 MOTHER'S FAMILY SIZE PLANS BY CHILD IS MONGOL

	No effect	No more children	Other	Total
Mongol	23	12	3	38
All others	64	31	11	106
Total	87	43	14	144

P = N.S. X^2 = 0.2280

There is no significance in the fact that almost two thirds (65%) of the mothers of Mongol children claimed that his birth had had no effect on their family size plans, although in an almost equal number of cases he was, in fact, the youngest child. (Table 101 - 5).

TABLE 101 - 6 MOTHER'S AGE BY CHILD IS MONGOL

	- 25	26 - 35	36 - 45	46 +	Total
Mongol	1	11	14	12	38
All others	2	56	42	6	106
Total	3	67	56	18	144

P = less than .01 X^2 = 18.5916

Not unexpectedly, proportionately more mothers in the 46+ age group now had born more Mongol children than in the other age groups (Table 101 - 6).

At the birth of the Mongol children the mean age of the fathers was 36.5 years, of the mothers 34.6 years, in comparison with the overall figures of father's mean age being 33.14 years, mother's mean age being 29.84 years.

TABLE 101 - 7 EFFECT ON SIBLINGS BY CHILD IS MONGOL

	No effect	Good effect	Bad effect	Other	Total
Mongol	11	16	11	0	38
All others	41	19	37	9	106
Total	52	35	48	9	144

P = greater than .01 X^2 = 10.9868

As if to bear witness to the popular belief that Mongols are good natured and fun to be with, 45.7% of the children judged to have had a good effect on their siblings were Mongols, whereas of those judged to have had a bad effect on their siblings only 25% were Mongols (Table 101 - 7).

No significant differences were noticed in analyses of the effect of Mongol children on the marital relationship or parents' estimate of their coping ability. Whilst parents of Mongol children aired their grievances about the diagnostic interview, no significant differences emerged when analysing counselling and support in the past, or counselling and support in the present. Having declared there to be no statistical significance, we must record the expressed opinion that 68% of parents with Mongol children alleged no counselling or support in the past, and 60.5% testifying to an unchanged state of affairs at present. The only evidence we could discover to account for this spirit of dissatisfaction, this sense of being unfairly discriminated against vis-a-vis the parents of spastic retarded children, for instance, appears in the two tables overleaf.

TABLE 101 - 8 PARENTS OF MONGOL CHILDREN NOW BEING HELPED BY PAST HELPERS

		Present Helpers			
		Medical	Educational	Voluntary Society	Total
Past Helpers	Medical	2	2	1	5
	Educational	0	2	0	2
	Voluntary Society	0	2	3	5
	Ourselves	0	2	0	2
	Total	2	8	4	14

TABLE 101 - 9 PARENTS OF MONGOL CHILDREN NOT NOW BEING HELPED BY PAST HELPERS

	Past Information	Past Support	Present Counselling/ Support	Total
Medical	13	12	0	25
Educational	6	2	0	8
Voluntary Society	2	1	0	3
Ourselves	3	9	0	12
Total	24	24	0	48

Comparing Tables 101 - 8 and 101 - 9 the following details emerge:-

	Times helping in past	Times helping at present
Medical	30	2
Educational	10	8
Voluntary Society	8	4
Ourselves	14	0
Total	62	14

As time wears on the medical information and support dwindle almost to vanishing point; educational information and support remain fairly constant, although reducing slightly; the value of the voluntary society's help decreases by half, and all the formerly self-reliant parents feel incapable of maintaining this front of independence. This group of parents have already been shown to register disproportionate dissatisfaction with the diagnostic interview. They often dislike a common reaction by their Family Doctor when they visit him with legitimate childhood complaints ("Oh, he's a Mongol. What can you expect?"). They criticise the dental services. Contrarily, they seem totally won over by the educational profession. Yet a great deal of this euphoria is directed at a small or non-existent speech therapy service; and over half the parents with a child in a Junior Occupation Centre were hostile at the lack of a Parent-Teacher Association. In the light of these qualifications it must be doubted how long their espousal of the educational profession will survive. On every count, parents of Mongol children seem highly at risk and much in need of counselling and support.

102.	Handicapped Child is Only Son	No.	Per cent.
	No	115	79.9
	Yes	29	20.1

Our attention was first drawn to the peculiar strains imposed on families with a handicapped only son by seeing in four such homes a painting of a boy in tears prominently on display in the sitting-room. In five cases within the 29, the handicapped only son was also the only child.

TABLE 102 - 1 DEGREE OF MENTAL HANDICAP OF CHILD BY CHILD IS ONLY SON

	No handicap Not sure	Some mental handicap	Severe mental handicap	Total
Only Son	13	5	11	29
All others	48	54	13	115
Total	61	59	24	144

P = less than .01 X^2 = 14.8942

Over half the parents with a handicapped only son admitted the child to have some or severe mental handicap, and just under half the children judged to be severely mentally handicapped were only sons (Table 102 - 1).

TABLE 102 - 2 ORDINAL POSITION OF CHILD BY CHILD IS ONLY SON

	Only	Oldest	Youngest	Middle	Total
Only Son	5	8	12	4	29
All others	1	19	54	41	115
Total	6	27	66	45	144

P = less than .02 X^2 = 11.3054

Analysed by birth order, five of the six 'only' children are only sons and only sons are over-represented in the 'oldest' category (Table 102 - 2).

TABLE 102 - 3 FATHER'S FAMILY SIZE PLANS BY CHILD IS ONLY SON

	No effect	No more children	Want another	Other	Total
Only Son	10	7	5	7	29
Other son	34	12	3	18	67
Daughter	27	7	0	14	48
Total	71	26	8	39	144

P = less than .05 X^2 = 13.0516

TABLE 102 - 4 MOTHER'S FAMILY SIZE PLANS BY CHILD IS ONLY SON

	No effect	No more children	Want another	Other	Total
Only Son	15	9	3	2	29
Other son	41	21	1	4	67
Daughter	41	13	1	3	48
Total	87	43	5	9	144

P = greater than .05 X^2 = 11.7061

The family size plans of the father (Table 102 - 3) and mother (Table 102 - 4) are analysed in those families in which the handicapped child is the only son. In the 'Want another' column appear five fathers and three mothers of only sons; one in seven fathers and one in six mothers of handicapped only sons claim his birth has had no effect on their family size plans, and approximately one quarter of fathers and mothers claim that since the birth of a handicapped only son they want no more children.

TABLE 102 - 5 FATHER'S RELATIONSHIP TO CHILD BY CHILD IS ONLY SON

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Only Son	5	10	9	24
Other son	8	15	26	49
Daughter	11	3	19	33
Total	24	28	54	106

Excluded from this table are the 38 fathers absent from the interview

P = less than .05 X^2 = 9.9327

TABLE 102 - 6 MOTHER'S RELATIONSHIP TO CHILD BY CHILD IS ONLY SON

	Protective Exclusive	Ambivalent Rejecting Withdrawn	Accepting	Total
Only Son	10	6	13	29
Other son	6	19	42	67
Daughter	14	10	24	48
Total	30	35	79	144

P = less than .05 X^2 = 11.0641

Analysing the father's relationship (Table 102 - 5) and the mother's relationship (Table 102 - 6) to the child when he is the only son fathers are 'positive' (i.e. accepting) towards more than one third of the only sons and 53% of other sons; mothers are 'positive' towards 45% of the only sons and two thirds of other sons. This is slight evidence, but it could indicate the measure of disappointment registered by both parents when their only son is handicapped.
No significant differences occur in the effect of the child on the marital relationship, on his siblings, in the interviewers' assessment of parental coping ability, satisfaction with the diagnostic interview; but in the counselling/support at present table a slight trend is noticeable.

TABLE 102 - 7 COUNSELLING/SUPPORT NOW BY CHILD IS ONLY SON

	No Counselling	Counselling	Total
Only Son	13	16	29
Other son	39	28	67
Daughter	34	14	48
Total	86	58	144

P = greater than .05 X^2 = 5.2015

Although the trend is not significant, proportionately more parents of only sons (58.5%) than of other sons (41.7%) and of girls (29.1%) receive counselling/support at present (Table 102 - 7). The helping professions, on this evidence, seem to respond to the stress of families with a handicapped only son; conversely, they seem to have a blind spot when the handicapped child is a girl, seven in ten such families claiming no support or counselling at present.

103. Psychologist's Assessment of Child's Educational Placement	No.	Per cent.
More handicapped (child would not benefit from Special School/Class, but is recommended for Day Centre of Junior Occupation Centre; child now in Gogarburn Hospital and not testable)	54	37.5
Less handicapped (child would benefit from removal out of ordinary school into Special School/Class)	55	38,2
Not tested or finally assessed (14) Not known to Psychologist (21)	35	24.3

The Edinburgh Child Guidance Clinic and West Lothian Education Committee's Teaching Development Centre were approached after the interviews had been completed. They kindly notified us of the proposed educational placement of the children whose parents we had interviewed.

TABLE 103 - 1 AGE AND CURRENT PLACEMENT OF CHILDREN NOT KNOWN TO OR TESTED BY PSYCHOLOGIST

	Less than 5	5 and over	Total
At home	3	1	4
Playgroup	14	2	16
Nursery School	5	1	6
Day Centre	2	1	3
Special School/Class	1	5	6
Total	25	10	35

Of the 25 less than 5 year olds 9 were known to the psychologist but not finally assessed and 16 were not known to the psychologist; of the 10 over 5 year olds half were known to the psychologist but not finally assessed and half were not known to the psychologist. Of the 21 not known to the psychologist 11 lived in Edinburgh and 10 in West Lothian. The nine Gogarburn 'patients' have been included in the 'More handicapped'category throughout, although the Hospital Psychologist could find no records of previous tests and was unable herself to test the children, so profoundly were they handicapped.

D Discussion of Methodology

Three aspects of the methodology employed merit discussion. First, is the questionnaire meaningful and logical? Secondly, are the parents' answers reliable, bearing in mind the complexity of some of the questions? Finally, how representative is the sample?

In the first place, the Departments of Psychology, Psychiatry and Social Medicine gave some advice on the range and type of questions, and the Social Sciences Research Council helped to make the choice options in any question both as specific and as comprehensive as possible. We gave much thought to the layout of the schedule, alternating sections of routine data collecting with sections of a potentially painful nature.

Data on the family was easily elicited, but data on the child took more time and occasioned some distress. Memories of the diagnostic interview were often upsetting; accounts of help received and services utilized reduced the emotional strain of the interview. Details of housing, income, child's present placement and so on were routinely collected; however, some parental anxiety surfaced in the section devoted to family size plans, child's effect on marital relationship, on siblings, on mother's social life. After assessing their own present coping ability parents considered the child's educational, employment and marriage prospects. A check list of the child's behaviour patterns was followed by the traumatic conclusion of the interview as the parents faced the issue of care for the child after their death or in the event of their incapacity.

Before the schedule was agreed on the medical supervisor of the project undertook a pilot run on six families. The researchers reported fully on their first twelve interviews. Two minor changes were made in the light of these early experiences; the question on "Counselling/Support in the past" was split into two questions, and the generalised query, "Are you presently receiving any help with the child?" became "Are you receiving the Special Attendance Allowance in respect of the child?" No further changes were deemed necessary since the schedule as administered seemed meaningful to the first group of parents.

Some questions were complex but phrased simply. "Which hand does he prefer to use?", for example, would be unsatisfactory to a paediatrician or neurologist. Obviously, a child with a paralysed right arm will not be right handed. However, our impression is that parents are next in line to physiotherapists in recognising the handedness of the child. Other questions appeared simple but had hidden depths. "How do you feel you are coping with X?" is an exceedingly complex question. Parents' answers would be influenced not only by their immediately past and present experiences with the child and his siblings, but also by the image they wished to present to two strangers.

The word which proved most unfamiliar to parents was "xounselling", and even when we defined it further some parents were not sure whether they had been counselled. Perhaps the hardest distinction the respondents were asked to draw was between how they reacted at present to the knowledge of the child's handicap and how they felt about or towards him. We explained carefully any question whose meaning was unclear to the parents but few found the interview unintelligible. One father, in fact, made a note of every question we asked before he answered it, and complimented us at the finish on the design of the questionnaire!

At this point we should explain that the researchers were told this was simply a fact finding exercise in respect of parental attitudes, experiences and needs. We were given no clue that the medical supervisor was interested in the light our survey might shed on the phenomenon of subcultural handicap.

In the second connection, the reliability of parents' answers, criteria are hard to determine. At the outset of each interview we told the parents that we had not seen any medical or psychological records of the child; that neither my colleague or myself was a doctor or teacher; that they could be as frank and honest as they liked in their answers and that any priorities they suggested for future services would be taken seriously. The Government was funding the survey and this Consumer Enquiry would indicate the best ways of spending the money newly being directed towards the handicapped and their families. We promised confidentiality, asked if we could make notes of any comments the parents made and sought to establish an empathetic relationship in each home. With all these preparations, however, we could not guarantee the truthfulness or reliability of the parents' answers.

There were twenty four homes in which the husband was absent from the interview, in addition to the fourteen homes with one parents (two widows, twelve separated/divorced wives). However, the logic of the questionnaire and its meaningfulness to a single respondent was not materially affected in these homes. Moreover, chi square tests specifically performed on these single respondent interviews revealed no distinctive patterns or significant deviations from the normal two respondent interviews. It is because one quarter of the interviews lacked their responses, however, that we have relatively downplayed the attitudes, needs and decisions of the husbands.

Parents in Classes I and II were more verbal, more graphic in describing their feelings, more detailed in their criticisms of the services and constructive in suggestions for improvements, and more realistic in certain assessments and expectations. Parents in Classes IV, V and Other were less verbal, less skilled in portraying their inner states, less cognisant and therefore less critical of the available services, and over-optimistic in certain assessments and expectations. There is a temptation to describe the first group of parents as more reliable because more verbal. One must distinguish, however, between those who had something to say and those who had to say something. In some of these homes, moreover, the interviewers felt they were witnessing a pre-arranged 'performance'; in others, we sensed the parents were liable to be 'over-truthful' about their burdens and disappointments because of the sympathy it would evoke and the benefits which might ensue. The equal and opposite tendency is to regard the second group of parents as less reliable because less verbal. In a few of these homes we seemed intruders engaged in a self-defeating exercise, asking questions which revealed the extent of our knowledge and the limits of theirs; such parents' failure to respond to our cues might have led us to be 'under-truthful' insofar as we attributed to them an unreal level of competence and contentment. We realised the danger of the 'halo effect' in which poor level of communication equals high level of satisfaction.

Notwithstanding these considerations, we believe that at some point in every interview we got as near to the truth as possible. Parents intent on concealment could not sustain this throughout, in part because of the

painful nature of some of the questions, in part, perhaps, because of the sympathetic hearing we gave them. Parents who assumed we were on a fool's errand gradually saw what the interview was about and with dawning realisation or from sheer exasperation became more outspoken and perhaps more honest in their answers. On the whole, however, most parents were undisguisedly grateful that someone had come to their homes, someone with experience of such children and their parents, someone who was prepared to listen as well as to talk, and someone who hoped very much that the help and advice given to parents of handicapped children in the future would be an improvement on the present situation.

To say that there was no point in deception on the parents' part is not, of course, to say that there was no deception on their part. To pretend that all the parents we interviewed were equally aware of the services, equally distressed by their situation, equally perceptive or truthful in their answers is patently absurd. By the nature of the case, more verbatims are presented in our findings from parents who had something to say than from parents who used words less and less well. We conclude, however, that the 'hard' data in our findings is reliable and that the 'soft' data represents fairly well the attitudes, needs and experiences of the parents we interviewed at the time of the interview.

Finally, how representative is the sample? The study necessarily excludes those who have hidden the problem from the education authorities and those who have opted to use private educational facilities. In the first connection, if parents decide to hide the problem - and hospitals still admit adult patients who have been kept in a back room for twenty five years - there is nothing we could do to identify such families.

In the second connection, there are virtually no facilities in the region apart from the Rudolf Steiner organisation and it does not usually take children of this age range into its residential units at Garvald and Camphill. It is possible that some parents in Classes I and II have arranged for their children to go to some educational/residential centre elsewhere in Scotland or abroad. Even if this were the case it would involve only a small number of families.

There is no means of producing statistical evidence of the number of mentally handicapped children in the prescribed age range living in Edinburgh and West Lothian who are unknown to the medical or educational authorities. With the exceptions and reason therefor noted earlier (p. 102) we interviewed a substantially representative sample of all such parents known to the authorities. In Edinburgh we interviewed all the parents who agreed to their names reaching us, whilst in West Lothian we chose not to interview a handful of parents whose child was less handicapped and who lived furthest from Edinburgh.

In summary, the schedule has an inherent logic, was meaningful to administer and was - or with further comment was rendered - meaningful to all the parents we interviewed. Alertness to the shifting dynamics in each interview, differences in language usage within different social classes, and acknowledged value judgments about verbalisation as a criterion of reliability, combine to make us cautiously optimistic as to the overall level of respondent reliability. The sample interviewed is as representative as possible of those families known to the authorities. From this discussion of methodology we turn to a brief discussion of the results.

E Discussion of Results

The objects of the survey were:- to discover parents' greatest needs, when these were most acute and how they might best be met; to isolate factors connected with the utliization or non-utilization of the available services, and to shed further light on the phenomenon of subcultural handicap. As noted above (p. 187) this third topic was not in fact disclosed to the researchers until the interviews and factorial analysis were completed.

A hierarchy of basic needs integral to his theory of human motivation has been described by Maslow (1). These basic needs are:-

physiological - especially with reference to hunger;

safety - the need for an organised and structured world;

belongingness and love - the need for contact, intimacy and togetherness;

esteem - the need for strength, achievement, etc. and for prestige;

self-actualization - become actualized in what one is potentially.

The preconditions for satisfying the basic needs are curiosity and understanding; the order of satisfying the needs can vary but usually occurs in the order outlined. For example, a person might have 85% physiological need satisfaction, 70% safety need satisfaction, 50% love need satisfaction, 40% self-esteem need satisfaction and 10% self-actualization need satisfaction. As one need is satisfied it is submerged and a new and higher need emerges. Moreover, what Maslow calls "gratification health" is "not only a series of increasing basic need gratifications, it is as well a series of increasing degrees of psychological health" (2).

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(1) Abraham H Maslow, 1970, Motivation and Personality, 35 - 58

(2) ibid., 67

In terms of this schematization, what parental needs did we discover? There are still parents for whom the physiological needs are scarcely satisfied. As well as the verbal evidence we had visual confirmation of the financial hardship and deprivation suffered in the homes of, for example, separated or divorced wives, widows, and unemployed men. Far more parents suffered through unmet safety needs. The world no longer seemed organised or structured since the arrival of a mentally handicapped child, an unexpected and unfamiliar event. The belongingness and love needs of parents are hard to assess on the strength of one domiciliary interview. Nevertheless, we detected in families with a mentally handicapped child:- strong affection between the parents; between the parents and all the children; between the parents and the handicapped child at the expense of his siblings, and vice versa. In other homes we registered a marked deficiency in affection, but could not unequivocally attribute this to the handicapped child. The esteem needs of parents with a mentally handicapped child are often unmet. To have produced a child evidently less than perfect reflects badly on the parents' strength and achievement (so the mythology goes) and does nothing to enhance their prestige and reputation - and even less in the future if the handicapped child is the only son. We can only hazard the guess that the self-actualization needs of certain parents are unfulfilled. The child disrupts expected family development plans, the father's work, the mother's social life, the siblings' chances, the planned family size ... and programmes them to perpetual parenthood of his perpetual childhood.

If Maslow is correct, and an unmet lower need blocks the appearance and articulation of a higher need, social class factors assume great significance. Any discussion of parental needs disclosed in our survey

must - in the summary as in the presentation - take account of the world as experienced by different groups within society. Single parent families will probably be short on need satisfactions at all levels. Homes with an unemployed husband, for example, may manage to satisfy the first three basic needs, but probably never aspire to the fourth and fifth needs. Upwardly mobile families, in our survey, seemed the most distraught as the child threatened the life-style of the parents and faced poorer life-chances than the parents had worked to make possible for him. These were the homes most deficient in terms of satisfied belongingness and esteem needs. Professional class families did not ordinarily display unmet physiological needs. They often exhibited protective/exclusive love towards the handicapped child, and frequently agonised over frustrated esteem needs. The preconditions of satisfying needs, a desire to know and the ability to understand, are equally class-related. This discussion reinforces the cautious note we struck with regard to the reliability of parents' answers. Verbosity is not synonymous with reliability, nor ignorance and lack of criticism with unreliability.

We will comment on four needs which were revealed by our survey. The first is the need that parents have of learning of their child's handicap in the best way at the right time. The majority of parents (64.6%) had been told before the child was three years old and in only 25.7% of the families were they told later than five years. Yet 42.4% of the parents denied that the child was mentally handicapped or said they were not sure of his handicap. In the case of all the severely handicapped children the parents were told by a doctor before the child was three. The parents of the less handicapped children were told in the main by a psychologist or teacher after the child had started school.

Paradoxically, those told early and by a doctor were more often dissatisfied with any or all of the following features, the manner, timing, content or comprehensibility of the interview; whilst those told later by a psychologist or teacher were more satisfied with the interview although some of them claimed never to have been told and what others were told did not register lastingly in their memories.

Our interpretation of these findings is that there are two quite different problems requiring different approaches. Parents of severely handicapped children should be told as early as is justified by diagnostic certainty, and in the context of an on-going relationship of counselling and support. This would suggest a team-work approach: doctor, social worker, health visitor, representative of a parents' or voluntary society an in appropriate cases the family's priest or minister. The parents should be told carefully, sympathetically and as clearly as possible. This information meeting should be followed up by support visits to the home over at least two years by one or more of the professionals present at (or part of the same team involved in) the diagnostic interview.

Parents of less handicapped children will inevitably learn late and frequently will find it easier to accept the news as they very often have another child already at special school. The problem here is not so much one of counselling as of more direct help in getting:- educational exposure for the child; the special attendance allowance if appropriate; assistance for the mother in improving her domestic and organizing skills, and perhaps family planning advice.

The second specific need worthy of comment is the child's educational and employment prospects. Many parents have an unreal expectation about the benefits of school-room learning and undervalue the benefits

of social learning. There is a genuine desire for more speech therapy which is not totally invalidated because of the misapprehension of the nature and extent of its merits. Probably it would help if all mentally handicapped children were allocated a pre-school nursery place, and if education continued after the age of sixteen years. Because the children in question were only just into the educational system, most parents were very unclear about employment prospects. Quite noticeably, however, the fear of the child when adolescent or adult 'getting into trouble' is linked with Classes IV, V and Other. The problem becomes maximal if not inevitable for teenagers who come out of special school and are unable to get work. Branded as failures to date, they can all too easily become successful in vandalism or violence. For such children a complete re-orientation of the later stages of secondary education towards vocational rather than academic-cum-literary goals would be beneficial. This pattern, indeed, is practised throughout Eire for all secondary school age children. Beyond school age, there should be a greater number of training centre places for them.

The third need parents articulated is the provision of residential facilities during the parents' life time and especially after their death. Parents differed about their present needs; some wanted their child away from home during the week and home at weekends, others wanted their child in a day school but boarded out at weekends. It is at least possible that were such a small residential-cum-educational unit established a rota system could be devised whereby both sets of parental needs could be satisfied. There was widespread parental concern as to the location and quality of care which their child-become-adult would need after the parents' death. We can add nothing to the heated debate ranging around this issue, except that 18% of the parents we interviewed

envisaged hospital care and only 12.6% knew about and/or preferred hostel type of care. Doubtless the results of Kushlick's Wessex experiment and an evaluation of the varities of Scandinavian facilities will influence the authorities in Scotland.

The last need we will comment on is the vexed issue of co-ordination and communication as seen from the parents' viewpoint. Child and adult psychiatrists, paediatricians; nursing staff in maternity hospitals, health visitors, district nurses; physiotherapists, occupational and speech therapists; teachers and psychologists; social workers attached to hospitals, local authorities or voluntary societies - these all find themselves in differing degrees involved in working with mentally handicapped children and their families. Two problems trouble the parents. In the first place, to whom should they turn for information and support if, as is often the case, the initiative is left to them? Secondly, could not more professionals visit their homes to help them in child-rearing skills, physical exercises and appropriate lessons for the child?

The provision of a multidisciplinary clinic with a high priority given to sympathy, clarity and availability would go a long way towards meeting the first of these needs. Increasing domiciliary services would obviosuly meet some of the criticisms in the second connection. We think that parental awareness of the dimensions of the problem; acquaintance with the facilities and the actual deliverers of professional help, and access to a centre where fellow-parents as well as concerned professionals could engage in mutual support - these measures would engender parental approval and co-operative effort of a high order. Furthermore, we recommend the formation of Parent-Teacher Associations in all centres where the mentally handicapped are nursed/supervised/

trained/educated. Parents need hope (perhaps Maslow's self-actualization need), and they exercise it so often in helping their child realise his potential that to exclude them from possible co-operation with his teachers is counter-productive if not heartless.

With regard to the domiciliary services we comment on two findings. With few exceptions the agent of information or support who earned most plaudits and least complaints was the health visitor. Conversely, the agent least seen by such families was the social worker. We believe it is not coincidental that health visitors are highly thought of and also visit families in their own home. The families in contact with a social worker lived in two areas of Edinburgh where the social work department had a neighbourhood rather than town centre office. More help and advice given in the home by professionals based in the neighbourhood seems desirable. It may be that the community health centres in liaison with locally based social work departments will exercise the functions parents themselves appreciate.

The discussion of what factors determine the utilization or non-utilization of the services has been virtually pre-empted by the demonstration of the inter-relationship of basic needs and social class. Another example of how needs expressed and services used are intertwined is in the realm of religion. Avoiding any reductionist tendencies, we can yet suggest that religion has to do with affirming the sanctity of life and inculcating attitudes of gratitude, trust and mutual support one of another. In an admittedly small sample, Protestants opted for educational and Catholics for voluntary society help and advice. Taken together these families claiming some religious affiliation seemed to utilize more services than families with no religious commitment.

In certain families the life-line was membership of a voluntary society. Parents of spastic children drew much support from the domiciliary visits of assorted professionals. Parents of mongol children, especially (but not exclusively) actively went out to seek and give support in a society comprised of fellow-parents rather than professionals. It is perhaps significant that in the case of spastics the need is affirmed by the medical profession because in limited ways doctors and physiotherapists can help, whereas in the case of mongols and other children the need is expressed by the parents who feel themselves unfairly left alone by doctors, teachers and speech therapists. Nevertheless, parents who have admitted a need and tried to meet it by active membership in a voluntary society are, in Maslow's terms, nearer gratification health than the misguidedly self-reliant and need-denying families.

Before discussing subcultural handicap we will comment on the other categories of mentally handicapped children delineated in our survey. The pathologically handicapped, although spread across the social classes, tend to cluster in Classes I and II. They evoke protective/exclusive attitudes in the mother and often the decision to have no more children. They are usually only or youngest children, never middle children. In none of these families was there another mentally handicapped sibling. These parents were told by a doctor and were often dissatisfied. However, they made good use of the services and more often than other social groups they received the special attendance allowance.

Apart from counselling and pre-school nursery places, the emphasis in this group should be on prevention. No less than 68% of the 38 mongols were born to mothers in the 36+ age group; if diagnostic amniocentesis had been freely available ten years ago in Edinburgh and West Lothian for older mothers, our mongol group could theoretically have been reduced from 38 to ten children.

The Class III children (in Birch's study - see p. 59) - these children more often had soft neurological signs suggesting minimal brain damage than the less handicapped children in Class V) present a very different problem. Expectedly, three quarters of these families are in the £20 - £34 per week income group. Mothers in Class III were proportionately more ambivalent or rejecting in their relationship to the child than other social groups. As we have noted, the upward mobility of these families is hampered by the presence of a mentally handicapped child and the ambitions cherished for him - that he should climb higher up the social ladder than his father - are frustrated. The polarisation of mothers into ambivalent/rejecting on the one hand, and protective/ exclusive or accepting on the other was exaggerated by the child's incontinence; 70% of ambivalent mothers had incontinent children as had 58% of the mothers who had decided to have no more children. Again, the majority of mothers in the ambivalent/rejecting category claimed that the child had curtailed their social life and 74% of these mothers were assessed as coping not well or well with stress.

It is unclear what should be done to help this group of families. The provision of betters services and counselling might help, although this is a group of parents from whom one might expect constant criticism, and for whom no provision would be good enough. In their case group therapy might enable them to ventilate some of their anger and project it onto a professional, thereby maximising the chances of the child himself being more accepted. So great is their commitment to achieving socially desired ends by socially approved means, however, and so greatly thwarting to those plans is a mentally handicapped child that full acceptance of such a child by his parents is very difficult.

The third object of our survey was to shed light on subcultural handicap. Birch et al (see p. 59) in their Aberdeen study concluded that subcultural handicap was not a blanket description of an entire class or classes but a subgroup within Class V. These parents were characterised by low social status and aspirations, minimal education, poverty, family disorganisation and unwillingness or inability to plan the major economic and marital aspects of their lives. They are, moreover, present- rather than future-oriented. The siblings of these mildly handicapped children showed a 12.8% incidence of mental subnormality and a 70% incidence of I.Q. scores less than 90. Only 41% of the fathers and 36% of the mothers of handicapped children currently in Class V had themselves been brought up in that class. From this evidence the authors postulated a 'drift theory' of downward movement into Class V of parents who may provide a poor genetic endowment or an inadequate environment, or both, for the development of their children.

In our survey we encountered in Classes IV, V and Other a preponderance of mothers showing an accepting attitude (perhaps fatalistic or submissive would be more accurate) towards their child. The child was usually the middle child and often already had a handicapped sibling. He was ordinarily right handed. The parents regard the child as not handicapped, are not sure, or claim never to have been told. The mother has not changed her family size plans because of the handicapped child, and the parents rate themselves as coping well without stress. More negative correlates are that fewer children have achieved continence, fewer spoke before the age of three years and fewer families had been granted the special attendance allowance.

Common to the parents in Birch's study and our own are the following characteristics. They practised less future planning; they evidenced less emotional distress; they were less curious and understanding (knowing less about mental handicap, the services, the child's likely educational and employment prospects); in a word, they experienced life as it was unquestioningly, perhaps uncomprehendingly, and could foresee no likelihood of their shaping, or things turning out for the better. Their overall level of social functioning makes them almost certainly identical with the 'problem families' known to every social agency.

Heber and Garber (3) have outlined a programme which aims at early, intensive infant stimulation followed by a structured pre-school education; in parallel the mothers underwent a rehabilitation programme aimed at preparing them for later employment and also at improving their skills in home making and child rearing. At the age of four and a half the experimental children were 27 points ahead on I.Q. as compared with the control group. The importance of this research lies in its recognition of the importance of the home environment. It, too, must be improved along with intensive educational opportunity.

Skeels (4) has followed up an experimental group of children who were adopted with a contrast group who remained in State Institutions. As adults the experimental group are all self-supporting; one has a B.A. and another graduated from business college. Of the contrast group five were still in guardianship and five resident in State Institutions.

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(3) R. Heber and H. Garber, 1971, An experiment in prevention of cultural-familial mental retardation, 31 - 35

(4) H.M. Skeels, 1966, Adult status of children with contrasting early life experiences: a follow up study

This work reinforces the suspicion that even if the genetic endowment these children get is not good, it is the social disadvantagement of the subcultural home which is the dominant handicap.

F Recommendations

> Using the Dutch pattern of domiciliary care and support, advice and counselling will need to be given to the parents when the diagnosis of retardation is first made. This is so that treatment provisions may be carried out successfully, and parents aided to adjust to the concept of retardation, and interaction between their needs and those of the child. In urban areas it may be possible to organize group meetings of parents, involve them in local associations to support one another, discuss problems, offer advice and arrange lectures. Health Visitors may be able to aid parents on the nursing care of the grossly retarded; skilled social workers may profitably lead discussion groups. Because the family of a retarded child is much tied by the child's needs, the social worker may need to make arrangements for holidays, short-term care, or other help when the family is severely stressed, such as by illness. At all times, the theme should be to try to keep the child within a loving, intact family, whilst giving them as much support as required. (5).

This comprehensive and admirable summary of recommendations made in a study completed six years ago in Wales encompasses all the recommendations we wish to make. Kuiterbrouwer (6) reports on the Dutch experience with its emphasis on infant home-training teams, consisting of paediatrician, psychologist and infant teacher, and the subsequent value of advisory clinics and ten day hospital units for young retarded children. Heaton-Ward (7) describes a multidisciplinary assessment clinic in Bristol; medical and nursing staff are augmented by occupational

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(5) M. Craft and L. Miles, 1967, Patterns of care for the subnormal, 132 - 133

(6) C. R. Kuiterbrouwer, 1965, Mental retardation and its welfare, (Utrecht: Catholic Bureau), quoted in Craft and Miles, ibid., 89

(7) W. A. Heaton-Ward, 1972, Assessment unit for the mentally subnormal 425-427

therapist, speech therapist, physiotherapist, clinical psychologist, social worker and remedial teacher in an ongoing process of assessment of the child and advice and support for the parents. Crowe (8) writes of a valuable service to be rendered by the voluntary societies. As a result of group therapy sessions over two years in Southend-on-Sea, the medical authorities have invited Crowe (herself the mother of a mongol) to attend the news-breaking interview for parents with a new born mongol. Within the week she makes a home visit to encourage both parents to adopt positive attitudes towards and activities with their child. In Glasgow the University Department of Adult Education and a Local Authority Education Committee jointly sponsor a series of evening lectures for parents and professionals. Topics covered include recognition of mental handicap, developmental milestones, relationships between voluntary and statutory services, viewpoints of parents and professionals, and so on. In Manchester a similar programme includes parents' workshops and group therapy (9).

If the recommendations which follow are implemented, Edinburgh and West Lothian will merely be brought into line with other parts of Great Britain; except, that is, for the final recommendation which we believe would be a pioneering project.

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(8) Barbara R Crowe, 1973, Notes on the running of group therapy for parents of mentally handicapped children in Southend-on-Sea, Essex, 15 - 19

(9) Details of the Glasgow programme are in the October, 1973 Newsletter of the Scottish Society for Mentally Handicapped Children. The Manchester project is under the auspices of the Hester Adrian Research Centre, University of Manchester, and the North West Region of the (English) Society for Mentally Handicapped Children. A booklet can be obtained from either source.

1. Establish a multidisciplinary clinic with the following functions:-

a) initial and ongoing assessment of the child

b) provision of a continuous counselling relationship for the parents

c) source of information for parents and professionals in the field

d) base from which domiciliary experts can operate.

2. Set up Parent-Teacher Associations in all centres where the mentally handicapped are supervised, trained or taught, thereby harnessing the desire and increasing the skill of parents to help their child realise his potential.

3. Provide a residential school at which certain children can be educated during the week and others boarded out at the weekend.

4. Enlist the help of voluntary societies and churches in providing:-

a) trained day-time child minders to relieve mothers with severely handicapped children in the home

b) foster parents for weekend and/or holiday relief guardianship of severely handicapped children.

5. Implement a project with the following aims:-

a) identifying 'subcultural' families in which the father's job (if any) is unskilled manual, the mother is less than 30 years old, there is one child already attending special school, the youngest child is under 12 months old and there is some evidence of general social incompetence (but not overt mental pathology)

b) match 30 'control' and 30 'experimental' families in Pilton and Craigmillar

c) place the 'experimental' children in pre-school nursery group and give them appropriate sensory training, play opportunities and language stimulation; invite the 'experimental' mothers to attend the training centre run by the Family Service Unit and increase

their domestic and organizing skills over a period of one to two years

d) ensure regular home visits after the two year attendance at the training centre so that mothers would continue to enrich the child's language store by use of radio, reading stories, etc.

e) measurement of change would take the form of:-

i. initial measurement of child's I.Q. and mother's I.Q.

ii. repeat testing of the child's I.Q. at six monthly intervals up to the age of five and annually thereafter until the age of ten

iii. repeat measurement of the mother's I.Q. when the child was aged five and ten years respectively. (10)

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(10) National Children's Bureau, 1973, Born to Fail? reports that by the age of 11 years, one in 14 disadvantaged children were going or were due to go to special schools. The incidence of disadvantaged children in Scotland is one in ten. Clearly, this makes the problem of subcultural handicap a priority for social, medical and educational intervention.
P. Wedge and Hilary Prosser are the co-authors of this Report.

Chapter 5 Reflections on and recommendations for the church's ministry to the mentally handicapped and their families

> Almost no writings are available which adequatelydescribe the relation of theology to mental retardation, the pastoral care of the retarded and their families, or the religious development of the retarded (1).

To Kanner's confession of professional bewilderment (p. 1), Bone, Spain and Martin's witness to public indifference (p. 34), and Olshansky's caution against potential cul-de-sacs (p. 65), we must add Stubblefield's admission to pastoral neglect. Theologians have not concerned themselves with mental handicap because they presuppose rationality on the part of their readers and (all too easily) on the part of those with whom God can enter into relationship. Pastoral counsellors have not specialised in working with the mentally handicapped both because they do not understand the normality which the retarded manifest, and because the unchanging state of their normality leaves little room for restorative skills and techniques. Religious educators have not grappled with the learning problems of the slow learner, even less the pre- or non-verbal and literate child; even the admirable curricula based on experiential models of learning are heavily slanted towards middle-class experiences, and the disadvantaged children are thereby effectively excluded from 'growing in the faith'.

All the articles we will review in this chapter are written from a Christian standpoint. Together, they raise issues which demand much re-thinking on the church's part and a considerable increase in its ministry to the handicapped and their families. We have chosen to present the material in such a way that the needs of the handicapped

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(1) Harold W Stubblefield, 1965, The church's ministry in mental retardation, 2

are considered before the needs of their families, whilst recognising that the opposite order makes equal sense. The precondition for satisfying needs is knowledge coupled with understanding. It is our belief that until recently the church has been markedly deficient in both these preconditions to the detriment of all concerned; the tide is turning, however, as the following pages demonstrate.

A The Needs of the Mentally Handicapped

> The church can provide a setting in which the retarded have the satisfaction that comes from belonging and succeeding - it can sustain them in the effort to reach their goals and provide non-threatening situations to help them develop emotional stability and socially acceptable behaviour.... the churches, with their belief in the uniqueness of the individual and in his worth, whatever his intellectual endowments, are the first line of defence against the sorrow and despair so frequently the lot of the retardate and his family (2).

Hauerwas (3), a Catholic moral theologian, raises the fundamental issue of the right of the retarded to life in the first place. He opposes the reigning humanism of the day which can call for the sacrifice of the few (weak) for the sake of the many (strong) in the name of 'humanity'. This he declares to be a power-hungry pretension and that "no humanity exists except as it is found in a child who must struggle to speak his name" (4). The Christian is called to love all men, not to be kind and helpful to as many as he can. If we give the handicapped the right to life we will discover that:- we are all valued in ways not dependent upon human strengths and purposes; we are confronted by a weakness analogous to God's

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(2) Ruth Latimer, 1969, Clergymen: what of the retarded?, 49 - 50

(3) Stanley Hauerwas, 1972, The Christian, society and the weak: a meditation on the care of the retarded, 1 - 11

(4) ibid., 9

that is, a weakness that does not control the more because it seems not to control at all; we see in the retarded a witness to something deeper than the God of order our world building requires; we can exercise non-possessive love (by loving the weak in Christ we dare to free them from our dependency on their need), and their strangeness awakens us to the strangeness in the depths of our being. He concludes:-

> The more Christians consider the fundamental issues raised by the care of the retarded, the stranger they will feel as they go about amid the glories and ruins of their own building. As we live with such strangeness, perhaps we will be better able to comprehend and love those who exist as strangers among us; they cannot understand as we can understand, but these retarded brothers are no less members of God's kingdom (5).

A similar plea that the retarded should be allowed the right to live appears in a letter from Peterson (Chaplain, Pacific State Hospital, Pomona, California) to this writer. Among other things he says:-

> I am startled by the fact that in our culture which is so oriented towards productivity, 1,500 people are caring for 2,000 virtually non-productive persons. This strikes me as a manifestation of another doctrine of man which is closer to that implicit in the Christian faith. In the light of the whole concern with ecology and the ultimate decisions which will have to be made about who is permitted to stay alive on this space-ship, Earth .... I know many of my sensitive colleagues would not hesitate for a moment to deny the retarded a seat on the Spaceship Earth (6).

A further need the mentally handicapped have, assuming they have been permitted to enter or remain in this life, is to live within the family circle wherever possible. Hoffman (7) demonstrates

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(5) ibid., 10 - 11

(6) Courtney Peterson, 1971, Letter to this writer

(7) John L Hoffman, 1961, Catholicism, medicine and mental retardation, 49 - 53

a real disagreement between, on the one hand, certain doctors and on the other hand, certain low income Catholic families, in respect of children with organically based mental handicap.

> The purely medical position here, regardless of sentiment for or against the child, is that the retarded child is the result of mischance, his individual physiology having lost in a game of Russian roulette played against an indifferent universe; the retarded child is a mistake which, in a medically ideal world, would not occur. The Catholic parents, although accepting physiological causes ... nevertheless accept at the same time another type of determination, that of divine origin. The child's misfortune may be seen as having either some direct reference to parental action, or as being a segment of a universal divine plan - a small, sombre stone in a vast mosaic - that cannot well be comprehended by the human mind (8).

If all men are potentially equal, he postulates, and the retarded child so clearly never can be equal, it takes no great leap of logic to assume he is less than human. In terms of how the parents 'see' the child (innocent and good in infancy, potentially imperfect at age seven); how they regard his trying as validating himself, and how they can bear pain and distress and exhibit sorrow, the parents differ from the doctors. They 'see' the child as neutral clay in the potter's hands; they believe that no matter how hard he tries he can never keep up with calendric development of specific achievement patterns, and they construe painful and distressing situations as not tolerable because potentially remediable. Driven by their "effort-optimism" the doctors regard the retarded child as irremediable and not to have possessed any potential to start with; therefore they advocate euthanasia of new born children because they are not perfectible. Alternatively, they may recommend that the home situation is or will become so intolerable that the child should

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(8) ibid., 50

be institutionalised. The parents, on the contrary, wish to accept and tolerate the child within the family circle.

Not only do the handicapped need the right to life and life within the family circle (wherever possible) they need the wider sense of belongingness within the church. Stubblefield presents an unexceptionable Protestant formulation of the church's message and ministry. Man is created in the image of God and the retarded, therefore, are persons not symbols. God accepts all men by grace through faith and not by works of righteousness. God's call is the same for every man, to achieve maximum potential as an individual and to serve God through his vocation (9).

He disputes Brunner's assertion that the "imago Dei" (basically centred in responsibility) "Only ceases where true human living ceases - on the borderline of imbecility or madness" (10). He criticises the practice of the Hutterites in 'cancelling the baptism' of two mildly defective individuals who had violated a number of religious rules (11). Nor does he approve the Lutheran doctrine

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(9) Stubblefield, op. cit., 1 - 11

(10) Emil Brunner, 1952, The Christian doctrine of creation and redemption, 57.
See also Paul Tillich, 1951, Systematic Theology, I, 259.
For these Protestant writers the equation is simple and final; no rational powers equals no religious consciousness.

(11) J.W. Eaton and R.J. Weil, 1955, Culture and mental disorders, 157. By cancellation of their baptism "they were reduced to the status of children, who are thought to be incapable of sinning and therefore can attain salvation automatically."

Of 8,542 Ethnic Hutterites in mid-west U.S.A. and Canada there were 15 idiots fed and cared for by families, 20 imbeciles who did some work and 16 working morons. "The sect give excellent personal attention to defectives and none have ever been institutionalised. Hutterites consider it a religious obligation to do everything possible to keep them well" p. 155

which elevates concepts above relationships when it states:-

> Nowhere does the Word of God excuse the exceptional child from the guilt of original or inherited sin, which is the total corruption of the human race. Like all infants, the exceptional child needs a Saviour from sin (12).

Stubblefield's conclusion is that in the retarded, religious consciousness and responsibility are relative to mental and chronological development. He sides with the Lutheran practice whereby only those can be confirmed who are ready to communicate and that means those who are baptised, are believers and are capable of self-examination.

For the Catholic, the child's baptism exposes him to divine grace which saves him "ex opere operato" and there is no essential need for the child-become-adult to understand his baptismal vows and seek confirmation and communion. For the Protestant, the child's baptism is the first step in a pilgrimage to salvation which ideally should see the child-become-adult come to personal faith and express this by requesting confirmation and communion. To re-state the truism: for the Catholic faith operates in the context of grace, for the Protestant grace operates in the context of faith. One way out of this impasse might be to follow Orthodox practice in the case of pathologically handicapped children of believing parents.

> Children are not only baptized in infancy, but confirmed in infancy and given communion in infancy. The child's earliest memories of the church will centre on the act of receiving the Holy Gifts of Christ's Body and Blood. Communion is not something he comes to at the age of six or seven (as in the Roman Catholic Church) or in adolscence (as in Anglicanism) but something from which he has never been excluded (13).

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(12) Providing a programe of Christian Education for the mentally retarded, undated, St. Louis Board of Parish Education, Lutheran Church, Missouri Synod, 23

(13) Timothy Ware, 1964, The Orthodox Church, 284, 286

Once their need to become and be seen to be a full member of the church has been met, the mentally handicapped share the common need to grow in the faith in terms of their understanding and service to others. Pruyser (14) suggests that in teaching, liturgics and the nature and organisation of religious thought the (Protestant) churches face much re-thinking.

> Has the church anything to offer to the mentally retarded? If the answer is negative, the church can no longer be regarded as the community which cares, the people who believe or the congregation which shares goods, gifts and sorrows (15).

The virtual absence of colour, smell and tactile sensations (saving occasional water splashing and wine sipping) in worship further handicaps those poorly attuned to verbal and auditory inputs. "The mentally retarded ... impose upon the church the duty to experiment with all its forms, joyfully and creatively." (16)

Henry (17) suggests that the church's responsibility for the Christian nurture of the retarded involves helping them pursue the goals of self-realisation, life adjustment and service to society. With their limited comprehension of language, limited attention span, limited area of experiences and limited ability to discriminate the mentally handicapped must perforce be taught slowly, repetitiously and in a way which reinforces their pride in mastering a thought or activity. "The aim must be to present a way of life rather than evincing a mode of thought".

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(14) Paul W Pruyser, 1966, IN Chakerian, op. cit., 10 - 25

(15) ibid., 16 (16) ibid., 22

(17) Fred E Henry, 1966, IN Chakerian, op. cit., 166

Loukes (18) is the one British writer we have discovered who has written on the church's responsibility for the less able pupil. He reinforces our own findings about social class and language usage and claims that disadvantaged children come from a family structure which is authoritarian, enjoys a narrow range and poor quality of relationships and affords less possibilities for creativeness. "They haven't much to talk about and wouldn't be able to talk about it if they had". However, he cautions himself,

> my talk of concept formation and intellectual apparatus sorts ill with the language of the gospels; the discussion of mental age seems out of harmony with Our Lord's injunction that grown men must become as little children (19).

The church must therefore perform a theological task in saying in empirical, this-worldly language just what it is Christians are talking about; a sociological task in determining the social structures (home, neighbourhood and school) in which social deprivation flourishes, and an educational task in expressing the findings of the first two exercises. His own blueprint for fulfilling the church's responsibilities (or in the terms of this section of the thesis, for meeting the needs of the mentally handicapped) is threefold in dimension. Build on the child's capacity to respond to affection. Build on his interest in his own personal situation. Build on his ability to serve the neighbourhood. In so doing, one will further be providing an opulence of talk.

> They need, more than any others, continual personal assurance and because they need it more, they can respond to it more directly and spontaneously. For them the Christian gospel will always have to be mediated by persons: they will always need to see the Person renewed in the personal (20).

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(18) Harold Loukes, 1965, The needs and potentialities of the less able pupil, 78 - 87

(19) ibid., 83

(20) ibid., 87

That the concept of mental handicap is wide enough to make the foregoing discussion on their Christian education not entirely meaningless, we share the findings of two chaplains of American Institutions for the Retarded. Stubblefield records that the educable and trainable (i.e. those with I.Q's in the 30 - 70/85 range) do conceptualise religious ideas, that the quality and number increases with mental age, and that all are anthropomorphic and related to real life situations. The trainable group believed God had human characteristics, that He was involved in their personal lives and that everyone shared religious concepts similar to their own. The educable group believed God had less human characteristics (i.e. God = Spirit), were more sure of His involvement in their lives and knew that others thought of God differently. For the retarded, sin and guilt were tied to concrete deeds and religion was seen as ritual and right behaviour; being a Christian and a church member met basically social needs (they love to be accepted and to participate), religion is invested by them with magical powers. Teachers of the retarded need to be emotionally mature and have a mature religious faith (21).

Perske (22) reprints some theological views expressed by his friends in hospital. A ten year old boy said:-

> Adam and Eve ate this apple that God told 'em not to eat. So God gets real mad at everybody. Then He sends Jesus and beats him up and gets it out of His system. Then He could love the rest of us again.

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(21) Stubblefield, op. cit., 53 - 95

(22) Robert Perske, 1971, The theological views of some of my mentally retarded friends, 45 - 48

A fifteen year old boy described the funeral service, and reproduced the rubric, "In the name of the Father and in the Son and in the hole you go!" A girl of the same age asked her parents, "Will I be retarded when I get to heaven?" They said, "No." "But how will you know me then?" she asked.

In view of the number of American articles quoted, it may come as a surprise to learn that even in America the church's involvement with the mentally handicapped is limited. Latimer (23) reports that of 925 churches and synagogues circulated in Ohio, Indiana and Kentucky one quarter replied and:-

> less than half the respondents provided religious education, and of these 38% had special classes, 30% had special teaching materials and 22% had teachers specially trained.

We suspect this reflects the uneasiness and inexperience of the ministers/priests/rabbis concerned. Peterson (24) analyses the results of 397 returned questionnaires from the clergymen of Denver, Colorado. In answer to the question, "Does knowing about mental retardation help to create a more positive attitude towards the retarded and their problems?", all who replied showed a low positive correlation (0.5) between knowledge of and attitude towards the mentally retarded. Factors affecting a change in attitude towards the mentally retarded included:-

clergy with four or more years college education scored higher on both knowledge and attitude instruments; clergy with personal experience and knowledge of a mentally retarded person scored higher

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(23) Latimer, op. cit., 49

(24) Courtney Peterson, 1970, More than knowing - Clergymen: their attitudes towards and knowledge of the mentally retarded, 24 - 26

on attitude instrument, whereas clergy with eleven or more years experience scored lower (0.5) than clergy with one to five years experience. Thus, he concludes:-

> The experience of clinical work in interpersonal relationships provides insights of a positive nature into the problems associated with mental retardation ... and the pastoral counselling courses ... may be providing a good deal of insight into the problems of other disabilities. Perhaps a concerted effort could be made to establish workshops, conferences or special instruction during their seminary training to increase ministers' knowledge of mental retardation.

Perske (25) accounts for the 'relationship gap' between the average clergyman (read the average person or professional) and the mentally retarded in these ways:-

he needs stimulating relationships; he has not learned to live graciously with failure; he feels threatened about his myths concerning human progress; he feels threatened regardings his own omnipotent feelings; he sees some people as the result of evil; he fears that he might appear stupid and insignificant, and he wants to keep his relationships within a narrow confine of people like himself.

If they overcome their hesitancy, develop techniques of non-verbal communication, and actuall work with the retarded they will learn from the retarded the wisdom of "seeking to move beyond the limits of their comprehension ... and admitting that they know their limitations" (26).

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(25) Robert Perske, 1968, The gap between the mentally retarded and the pastor, 160 - 167

(26) Perske, 1969, Ministry and mental retardation, 26

The way in which the retarded confront those nearest them with their limitations is commented on in a separate series of articles. Stubblefield (27) writes that the world of the retarded is a limited world; a dependent world; a world of over-reactions and responses to situations; a world in which they know they are the object of someone's disappointment, and a closed world, struggle though they may to get out of it. The pastor should help them cope with life, make sense of it and make appropriate relationships. He should also deal with their sense of failure, grief, loss and guilt, and help them form a meaningful faith (such as Erikson's 'basic trustworthiness'). He can attend to them, encourage and enable them to realise their potential by utilizing their own, the pastor's and the particular environment's resources.

Newbigin argues that in ministry among the marginals (he has in mind the poor of India as well as the weak and handicapped) one receives more than one gives, and that something precious is passed both ways and mutual respect is enhanced. Moreover, as the gap is widening within the developed as well as between the developed and developing societies between those who can tolerate the strains of development and those who cannot, "something vital is lost to the total health of society if the values of the strong and successful are the only ones which are respected" (28). He concludes with these words:-

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(27) Stubblefield, 1970, On being a pastor to the mentally retarded, 98 - 108

(28) Lesslie Newbigin, 1971, The unity of the church and the handicapped in society (ed., Gerald F Moede), 8

> We need a model which is shaped by the mystery of the Cross - embodying BOTH rebellion to the limit against all that dehumanises man AND recognition of the fact that there is a limit, and that at that limit there is to be found - by grace - a blessing without which the life of society is not fully human.(29)

Mimus takes up the theme of the aspect of God to which the retarded witness, first mentioned in Hauerwas (p. 308) and echoed by Newbigin. In a Bible study on II Corinthians 12 he claims that this and related passages affirm:-

> that human weakness is a more fit vehicle and a more convincing sign of God's power than is human strength. There is in human weakness a special receptivity to divine power and a transparency which is able to make that power manifest (30).

What is more, he continues, the reason we engage in distancing ourselves from the handicapped is that "we continue to prefer illusion to reality; we prefer to believe that we have transcended our creaturely, dependent nature. We need such people in our midst so that they can help us to learn the truth about ourselves and our destiny".

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(29) ibid., 8

(30) Paul Mimus, ibid., 5

In a preparatory document published in 1970, Moede states:-

> If the church becomes primarily concerned and identified with those who <u>do</u>, those who <u>control</u>, does it not become part of the machinery of segregation? Is it not then confirming the general expectation of society that it is the healthy (or those who can be restored to health) who constitute the norm? Seen in perspective, all concrete human experience and all concrete human possibilities are limited. Some human beings are so limited or handicapped that they are liable to become marginal in society. What is and what should be the response of the church to, and the responsibility of the church for, these people? (p. 10)

Howard (32) shares two private musings in her article from the same document. First, what light is thrown on this whole subject by the curious change in meaning the word 'handicapped' has undergone? From being 'extra weight imposed on a superior competitor' it has come to mean simply ' a disadvantage'. Secondly,

> do the handicapped challenge the activist assumptions of much contemporary church life which seems to assume that Christians ought always to be a highly organised, articulate and mature group of people helping or seeking to help others, rather than a community which seeks to integrate within itself the weak and powerless and inadequate as well as the strong and active?

In this section we have attempted a Christian statement of what mental handicap implies for the handicapped, the church and society. They need to be given the right to life. They need, in life, the right of living wherever possible within the family circle. They need to live in an integrated way within society rather than on its margins. They confront us with our own limitations and dependent natures. They need to be made and to grow as full members of the church. This entails the church in the exercise of clarifying its doctrine of salvation; ensuring appropriate means by which the mentally handicapped can grow in their understanding of the faith, character formation and useful service to their fellows; and coming to an understanding of its own nature which enables a real and not merely formal two-way interactive process between the (so called) strong and the (so called) weak. To spearhead this reshaping of its life, ministers will need to become personally acquainted with the mentally handicapped and their strange world, and hopefully learn as much from them as possible about gratitude, enthusiasm, joyfulness and endeavour.

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(32) Christian Howard, 1971, Moede op. cit., 5

B The Needs of Families with Handicapped Children

> Receiving a mentally retarded child into the family arouses anger, not only diffusely at the scheme of nature, at fate or at God, but also specifically at the marital partner, the parents or grandparents of either spouse, and the child himself. Dealing with these dynamics of anger, by recognising them without judgment, then by channeling them through directed thought and activity, is one of the major pastoral tasks... Mourning has to occur for the unborn, idealised child; but mourning has also to occur, in a different sense, for the damage and deformities of the real child that was born (33).

We have noted in Farber's study (pp 88 - 89) that Catholic definition of home and family life and/or participation in a Catholic church proved supportive, whether the mentally handicapped child was at home or in an institution. Hoffman (p. 308) has similarly noted that Catholic doctrine and (if a separate entity) piety can bring much in the way of absolution and reassurance to the mother as well as inculcating a positive attitude towards the child. Lenski (34) claimed that of 656 Detroit families interviewed, 68% of Catholic mothers compared with 51% of Protestant mothers regarded child rearing as pleasant or very pleasant; Protestant parents more often than Catholic parents valued intellectual autonomy in children more highly than obedience.

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(33) Pruyser, op. cit., 20

(34) Gerhard Lenski, 1963, The religious factor (New York: Doubleday) quoted in Stubblefield, op. cit., 15
The children in Lenski's famous study, incidentally, were not necessarily or even mainly handicapped. His findings corroborate the impressions gained generally and would suggest that for Catholic parents to accept a handicapped child is not acting out of character, nor using their religion pathologically.

Zuk reported on the responses of 76 parents in Philadelphia to their handicapped child (39 Roman Catholic: 38 white and one Negro - 37 non Catholic: 19 white and 9 Negro Protestant, 9 Jewish). There were no significant correlations between intelligence or social class and acceptance, yet independent assessment confirmed his assessment that whereas 25 out of 35 Catholic mothers were accepting, this was true of only 5 out of 37 non-Catholic mothers. He concludes that guilt is a central dynamic problem in impeding adjustment to the child in non-Catholic mothers, whereas:-

> Catholic doctrine provides considerable emotional support for mothers by its insistence that every child, normal or defective, is a special gift of God bestowed on the parents. Indeed, the birth of a retarded child may be perceived by the devout Catholic mother as a unique test of her religious faith (35).

Hyde (36) presented the results of 100 interviews with parents of retarded children at a short-term institution for the retarded in a small Ohio town. There were 40% each of Protestant and Catholic and 3% Jewish families, the remainder having no religious affiliation; 80% (not coterminous with the joint Protestant/Catholic population) claimed religion as a help in accepting the child; 66% had chosen not to seek their minister's help, 27% had sought his help and been helped and 7% had sought his help and received none; the families reported that the effect on their faith of having a retarded child was 'no change' in 46% of cases (because they never had a real faith or because they were still too numb, Hyde posits), more faith in 36%, less faith in 10% and 'not known' in the remainder of cases.

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(35) G. H. Zuk, 1959, The religious factor and the role of guilt in parental acceptance of the retarded child, 145

(36) C. E. Hyde, 1969, Use of a religious questionnaire in initial chaplain interviews with a retardate, 88 - 96

Stubblefield interviewed 220 Protestant and Catholic clergy as to the effects they had observed in the faith of parents who had a mentally retarded child. Surprisingly, perhaps, 41% said they had seen faith stimulated in these parents, 28% said that families had been brought closer to the church; against that, however, 15% knew the retarded child had disturbed the parents' faith in the goodness of God, and 13% noted reactions of guilt in the parents which, if unresolved, led to bitterness and apathy. The author concluded that the majority of these parents "lived at deeper levels of patience, humility and gratitude and developed a strange kind of courage" (37).

It is perhaps their lack of a doctrine and technique of absolution that makes Protestant families less able to adjust quickly and positively towards their handicapped child than Catholic families. We suggest that they not only blame themselves (or God) for producing such a child but also dread the perpetuation of their shame insofar as the child cannot make a rational assent to the preached gospel nor live a life worthy of his calling by serving his fellows. All the ramifications of the Protestant 'work-ethic' spread as a general depression over their religious certainty, self-esteem and hope. If their faith is a necessary 'saving' response to God's grace, what hope has their child of reaching that faith? If such a response of faith is not necessary for their or his 'salvation' how can they be sure of God's grace, especially if they baulk at sacramentarianism?

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(37) Stubblefield, 1965, Religion, parents and mental retardation, 8

The role of the minister in dealing with parents of retarded children has been written up mostly by Americans who are or have been chaplains in State Institutions. We quote first, however, from a paediatrician. Blue writes with much insight and reassurance:-

> Ministers must recognise that their own negative feelings which are aroused by the disabled, and the discomfort associated with the birth of a defective, are not indictments of their worthiness as God's representatives, but, rather, are related to their very real earthbound and socially dictated, long-standing attitudes which have only recently broken from the bonds of superstition. The sin is not in having these feelings, but in having one's actions dictated by them (38).

He commends the philosophy on mourning stressed by Solnit and Stark (p. 84), and argues from the basis of Stein's definition of "catastrophic illness" (39):-

> The very first days are crucial ones, and the minister that makes himself available to the parents during that time in a supportive listening-post role will produce more positive results than will many sessions of counselling in the later years of that infant's childhood (40).

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(38) C Milton Blue, 1971, The minister and the birth of a defective child, 48

(39) E. V. Stein, 1966, The role of the clergy in catastrophic illness, 24. The definition is:-
Catastrophic illness is any illness that has massive effects on the body, mind and spirit of the patient, and that cannot be rather quickly, surely or permanently alleviated by medical skill.

(40) Blue, op. cit., 50
In this outstanding article he further defines the necessity of crisis intervention counselling; because the unknown has occurred and man can only search through the unknown by way of his God; the parents' present and future mental health depend on immediate care to help move them through the guilt and shame-inducing shock period to a more constructive period, and the development of a healthy self-concept in the disabled is highly dependent on the attitudes of the parents towards the child - their guilt can cripple him as he develops.

Perske suggests that if the minister understands and accepts the retarded person he can understand better unconditional grace. In his dealings with the family he should encourage all the family members to work kindly and affectionately in setting realistic functional limits for the child; encourage them to thrill in small gains, and sustain them in a situation which scarcely moves or changes at all. Perhaps the best thing Perske has written in a series of articles reminiscent of the curate's egg is that "the mentally retarded never know they are a tragedy until they see it in our faces and our actions" (41).

Stubblefield recommends that the minister should encourage the parents to become involved with fellow parents; help break down the social isolation so typical of these families; help the family clarify its feelings and localise specific problems; help them locate and mobilise resources, and discourage over-protection (often a device for atoning one's assumed guilt) whereby parents "play God" by letting no one else care for the child. "The pastor may need to remind the family that the proper object of worship is God, not the retarded child" (42).

Pruyser (43) echoes Blue in his estimate of the "crucial situation of the first interview when the parents seek some meaning in their overwhelming grief, resentment and rejection".

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(41) Perske, 1968, The pastoral care and counselling of families of the mentally retarded, 24

(42) Stubblefield, 1965, op. cit., 48

(43) Pruyser, op. cit., 20

Both Perske and Stubblefield used the word 'sustaining' in their writings, and this concept is best expounded by Hiltner (44):-

> By sustaining is meant that aspect of the shepherding perspective that emphasizes 'standing by'. Unlike healing, in which the total situation is capable of change, sustaining relates to those situations that as total situations cannot be changed or at least cannot be changed at this time .... Broadly speaking, the ministry of sustaining becomes dominant in two types of situations; when there is shock or loss and when some irreverisble process of impairing or degenerating is at work .... Sustaining ... does not sustain if it settles too easily for supporting, for supporting turns readily into dependency. Yet sustaining, if it really sustains, is itself healing within the limits of circumstances (45).

Clebsch and Jaekle (46) cover similar ground in their definition of sustaining as one of the church's four ministries of counselling. It has four components:-

> Preservation - holding the line against other threats or further loss, or excessive retreat:
> Consolation - relieving misery by bringing the sufferer into an understanding of his still belonging to the company of hopeful living:
> Consolidation - regrouping the remaining resources despite loss, putting suffering into perspective within the totality of living:
> Redemption - building an ongoing life that once more pursues its fulfilment and destiny on a new basis.

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(44) Seward Hiltner, 1958, Preface to Pastoral Theology, 116 - 144

(45) ibid., 116, 117, 143 - 144

(46) Clebsch and Jaekle, op. cit., 8 - 9

Further examples of supportive counselling, specifically with lower socio-educational groups, are given in Clinebell's major text book (47). He himself speaks of "the remarkable changes which occur in the person's ability to live constructively with the 'givenness' of his situation when acceptance replaces an attitude of brooding bitterness or self-pity" (48). White describes how:-

> Many of the poor do not express themselves well. They do not see how 'just talking about it' can resolve their problems. Their concerns are immediate, concrete and pressing. They need to see fast, though limited improvement (49).

Riessman evaluated a new mental health treatment for the poorer groups, concluding:-

> Those who will leave their offices and relate to their patients informally in their place of work, in the family setting, in informal street visits, etc., soon become trusted members of the patients' community. The poor person welcomes direct intervention during his time of crisis.. The psychological difficulties of many low income patients diminish as they become involved in some meaningful commitment, whether it be a religious activity, a hobby, a labour union, or participation in a block committee (50).

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(47) Howard J Clinebell, Jr., 1966, Basic types of pastoral counselling, 139 - 166

(48) ibid., 148

(49) Dale White, 1964, Mental health and the poor, Concern, October 15th, 6 quoted in ibid., 152

(50) Frank Riessman, undated, Columbia University, Survey for National Institute of Labor Education, quoted in White, ibid., 6 - 7

We take the liberty of applying the work of White and Riessman to the subcultural group of families; whether this is justified does not seem to vitiate the sound common sense of their descriptions and prescriptions.

Hampton, herself the parent of a nine year old retarded girl, remarks that "retarded children and adults need to feel wanted and church life is important for them"; churches might start group therapy classes for parents of retarded children, and the church in all its educational, recreational and worship activities should 'mix' normal and handicapped persons for the benefit of both (51). Pruyser reinforces this when he urges that congregational support for the retarded should ultimately take the form of:-

> a complete and unabashed visibility of the retarded in the congregations, not only for the sake of those who are hungry for acceptance, but for the sake of the congregation as a whole. Christianity knows no 'untouchables'; it is meant to be an embracing demonstration of reconciliation (52).

The reshaping of all the church's forms should be undertaken ecumenically, partly because individual churches neither have enough retarded 'members' nor trained teachers, but mostly because "the issues at stake are not points of polity or theological finesse, but the most profound human problem that has always faced mankind: the problem of pain and suffering" (53).

Stubblefield comments briefly on the social welfare obligations of the church, urging that where new facilities cannot be built "local churches and individual church members could provide foster homes." (54)

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(51) Dorothy L Hampton, 1964, Retarded children and Christian concern, 13

(52) Pruyser, op. cit., 21

(53) ibid., 21

(54) Stubblefield, op. cit., 142

Once it is informed, moreover, the church can be prophetic in calling for legislation and social action.

> In its social welfare role the church champions the right of this neglected minority to have adequate care and treatment through services provided by the community and the church. Underlying this concern is the belief that only concrete services which meet the needs of the whole man are adequate manifestations of the church's missionary and social responsibility (55).

Any church which so informed itself and called for action would be well advised to read Voelkel's concise statement of 'environmental ministries'. Distinguishing social service (the normal Christian "diakonia") from social change (a continuum running from democracy through non-violent resistance to revolution) he outlines the following strategy:-

what is the social problem? utilize the 'victims', change agents, decision makers and experts, in that order:

what is your action goal? think of urgency, significance, extent and feasibility in light of the resources:

what is your plan of action? learn of parallel efforts, learn how to organise, learn how to build and support teams:

what are you learning which confirms or contradicts your goal or plan?

evaluation and research must be practised pari passu. (56)

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(55) ibid., 144

(56) W. R. Voelkel, 1970, Creating human environment: Mission for the seventies, 14-29
There needs to be a social vision and a theology of social change, with a confessional component (declaring one's commitment), an ethical component (both critical and constructive) and a religious component (a ritual for expressing the ultimate concerns of those engaged in social change activities).

As Gill observes (57) it is odd that pastoral care should be going more and more one-to-one as medical care is going more and more community-oriented! In his essay on deviance, he cites the famous theories of Merton, Cohen, Parsons and Goffman; quotes Berger's definition of the church as itself deviant (by virtue of its own goals and means), and argues that as the model of the Kingdom of God is a goal it is strange that the church should function as a supporter, an upholder of means.

> I have argued on both sociological and theological grounds that a social perspective will provide a better basis for the pastoral ministry than a clinical perspective. My concern is with centrality ... The social perspective is in desperate need of exploration (58).

In this section we have outlined the needs of the parents with mentally handicapped children. These include the need to have their own faith shored up in face of the floodwaters of grief, guilt and gloom; the need for a sustaining relationship over a protracted period; the need to avoid social isolation and child 'worship' as a compensation; the need to see their child fully accepted within the life and work of the church, and the need to know that the church is not only calling for but working for the continuing and improved care of the mentally handicapped. We state the obligation on the church to provide adequate seminary training, in-service refresher courses, and so on, with regard to crisis intervention and long-term supportive counselling skills. We argue that hand in hand with its commitment to pastoral

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(57) Robin Gill, 1973, Pastoral care and the sociology of deviance, 2 - 9

(58) ibid., 9

counselling the church, especially in areas of urban squalor where subcultural handicap thrives, should gear itself towards a ministry aimed at social change. Finally, the programme suggested could be undertaken on an ecumenical basis with a neighbourhood emphasis.

C Recommendations for Action and Research

We are emboldened by MacMurray's dictum - "all meaningful thought is towards action and all meaningful action is towards friendship" - to make a few recommendations for action at present and research in the future. The inspiration behind the recommendations is mainly the first hand experience gained in interviewing the families and the two year appointment as assistant chaplain at Gogarburn Hospital. A contributory factor is the alarming picture we have painted of ecclesiastical ignorance, discomfiture and neglect; the church's preoccupation with rationality and perfectibility has worked against the irrational and imperfect persons in society. It is our conviction that more knowledge can lead to more understanding and more understanding can issue in more action. Furthermore, we believe this thesis has merely opened up a hitherto unexplored territory, and that rich rewards await the handicapped as well as the church if more research is carried out. In the profoundest and least sentimental sense, how we react towards and relate with the mentally handicapped can serve as a model of how God feels about and deals with us.

1. Create awareness in ministers of the problems faced by families with a mentally handicapped member by means of:-

a) special instruction, workshops, conferences, visits to day centres and residential facilities (including hospitals) for the mentally handicapped, etc., as part of ministerial training

b) extending these learning experiences to ministers, deaconesses and other full time church workers

c) articles in widely read religious journals of all denominations

d) providing specialist training for ministers with interest and native skill in such areas as:-

i. counselling parents of handicapped children

ii. communicating the faith to the mentally handicapped

iii. chaplaincy work among the mentally handicapped

2. With ministers alerted to the problems and opportunities, churches working together in an agreed area should determine the number and identity of families with a mentally handicapped child and offer the following types of assistance:-

a) baby sitting during the day and the evening

b) a limited number of places in church-run play groups

c) perform a bridging operation by means of which:-

i. all such families in the area can be put in touch with each other for mutual support and possible group therapy

ii. a rota of families with normal children can be set up to assist and befriend families with a handicapped child with the eventual possibility of relief weekend fostering

d) select and train one or two Sunday School teachers within the area for working with mentally handicapped children

3. Volunteers could be drawn from churches to help in hospitals for the mentally handicapped, offering to supplement existing or innovate new services as the hospital determined, such as:-

a) visiting 'friendless' patients as frequently and regularly as possible, with a view to inviting the patient to their home for a meal, etc.

b) providing 'mothering' for the multiply handicapped young children, e.g. cuddling, feeding, changing and playing with them

c) encouraging the more able patients to join in the worship, educational and recreational activities of neighbouring churches

4. Research could valuably be undertaken in the following areas:-

a) the effect the birth of a handicapped child has on the faith of the parents; comparing different religious groups; seeking to distinguish between a healthy and a pathological use of religion, and measuring the length of time any undermining effects persist and what factors influence a restoration of faith

b) the effect on Protestant theology of mental handicap with regard to:-

i. the forgiveness of parental guilt

ii. the acceptance into church membership of those persons lacking reason; criteria for eligibility to receive communion; objects and methods of religious education, etc;

iii. implications of their short concentration span on the structure and their sensory needs on the content of worship

c) the opportunity mental handicap affords for bridging the gaps between denominations, and between pastoral counselling and social change as ministerial commitments.

Our thesis has presented a panoramic view of social and ecclesiastical attitudes and treatments prior to the nineteenth century. A closer look was given at the professional constructs and policies which have marked the hundred and seventy years since then. We attempted to define mental handicap in its pathological and subcultural varieties and estimated its prevalence. Differing approaches to working with families having a mentally handicapped child were reviewed. An intensive and extensive survey was reported into the attitudes, experiences and needs of parents with a mentally handicapped child in the under eight age range living in Edinburgh and West Lothian. In conclusion, we summarised the most recent (and mostly American) literature on the responsibility of the church towards the mentally handicapped and their families. Recommendations were made of both a political and theological nature.

> The mentally handicapped are not asking for much. All they want is a chance to grow and develop within their own limitations, a chance to be useful, a chance to love and to be loved, and a chance to know God as we have had a chance to know Him (59).

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(59) Carl J Rote, 1966, Counselling: How to cope with mental retardation, 15

Appendix A

A Copy of the Interview Questionnaire as administered to the Parents

C A R D I

NAME .....

ADDRESS .....

DATE .....

PART I - DATA ON PARENTS

1. Interview Code No, — Cols 1 - 3

2. Date of Birth of Index Child — Cols 4 - 9

3. Birth Weight in lbs and ozs — Cols 10 - 13

4. Sex of Index Child — Col 14
   1. Male
   2. Female

5. City Ward No. in Edinburgh — Cols 15 - 16

6. Father's Present Age — Cols 17 - 18

7. Father's Job (i.e. Social Class) — Col 19
   1. Class I
   2. Class II
   3. Class III
   4. Class IV
   5. Class V
   6. Unemployed
   7. Other
   8. Not known

8. Father's Present Health — Col 20
   1. No complaints or disability
   2. Complaints only
   3. Complaints and disabilities
   4. Complaints and disabilities and in hospital
   5. Other
   6. Not known

9. Mother's Present Age — Cols 21 - 22

Col 23

10. Mother's Job

1. None
2. Part-time
3. Full-time
4. Other
5. Not known

Col 24

11. Mother's Present Health

1. No complaints or disability
2. Complaints only
3. Complaints and disabilities
4. Complaints and disabilities and in hospital
5. Other
6. Not known

Col 25

12. Psychiatric Illness in Father's Family

1. No
2. Parents in Psycho Hospital
3. Parents psycho at home
4. Sibling in Psycho Hospital
5. Sibling psycho at home
6. Other relative in Psycho Hospital
7. Other relative psycho at home
8. Other
9. Not known

Col 26

13. Psychiatric Illness in Mother's Family

1. No
2. Parents in Psycho Hospital
3. Parents psycho at home
4. Sibling in Psycho Hospital
5. Sibling psycho at home
6. Other relative in Psycho Hospital
7. Other relative psycho at home
8. Other
9. Not known

Cols 27 - 28

14. Number of Children now alive

Cols 29 - 30

15. Number of unsuccessful pregnancies (abortion, miscarriage)

Cols 31 - 32

16. Ordinal position of Index Child among Siblings

Cols 33 - 34

17. Age of Mother at birth of Index Child

Cols 35 - 36

18. Age of Father at birth of Index Child

PART II - DATA ON CHILD

Col 37

19. Degree of Mental Handicap

Specify diagnosis if known to parents

1. Not mentally handicapped
2. Mentally handicapped
3. Severely mentally handicapped
4. Other
5. Not known

Col 38

20. Degree of Physical Handicap

Specify diagnosis if known to parents

1. Not physically handicapped
2. Physically handicapped
3. Severely physically handicapped
4. Other
5. Not known

Col 39

21. Degree of Mobility/Continence

1. Mobile, continent
2. Some limitation, continent
3. Mobile, incontinent
4. Some limitation, incontinent
5. Severe limitation, incontinent
6. Totally helpless, always incontinent
7. Other
8. Not known

Col 40

22. Current Health of Child

1. No complaints or disability
2. Complaints only
3. Complaints and disabilities
4. Complaints and disabilities and in hospital
5. Other
6. Not known

Col 41

23. Has your Child any Impairment of Vision?

1. No
2. Partial sight
3. Blind
4. Other
5. Not known

Col 42

24. Has your Child any Impairment of Hearing?

1. No
2. Partial deafness
3. Deaf
4. Other
5. Not known

Col 43

25. How old was your Child when he first used Words?

1. Less than 12 months
2. 12 - 23 months
3. 24 - 35 months
4. 36 - 47 months
5. 48 - 59 months
6. 5 years or more
7. Never
8. Other
9. Not known

Col 44

26. How old was your Child when he first used Phrases?

1. Less than 12 months
2. 12 - 23 months
3. 24 - 35 months
4. 36 - 47 months
5. 48 - 59 months
6. 5 years or more
7. Never
8. Other
9. Not known

Col 45

27. How old was your Child when he first used Sentences?

1. Less than 12 months
2. 12 - 23 months
3. 24 - 35 months
4. 36 - 47 months
5. 48 - 59 months
6. 5 years or more
7. Never
8. Other
9. Not known

Col 46

28. Has any other relative a slow speech start?

1. No
2. Yes
3. Other
4. Not known

Col 47

29. Which hand does your Child prefer?

1. Left hand
2. Right hand
3. Both hands
4. Other
5. Not known

Col 48

30. Has your Child been subject to fits?

1. No
2. Yes
3. Other
4. Not known

Describe frequency

Col 49

31. Have you any other child with mental handicap?

1. No
2. Yes

Col 50

32. Have you any other child with psychological illness?

1. No
2. Yes

Specify

Col 51

33. Have you any other child with physical illness?

1. No
2. Yes

Specify

Col 52

34. How old was your Child when you were told he was handicapped?

1. Less than 12 months
2. 12 - 23 months
3. 24 - 35 months
4. 36 - 47 months
5. 48 - 59 months
6. 5 years or more
7. Never told
8. Other
9. Not known

Col 53

35. Had you known before you were told?

1. No
2. Yes
3. Not applicable (because never told)
4. Other
5. Not known

Col 54

36. If YES to No. 35, what was Child's age when you knew he was handicapped?

1. Less than 12 months
2. 12 - 23 months
3. 24 - 35 months
4. 36 - 47 months
5. 48 - 59 months
6. 5 years or more
7. Not applicable
8. Other
9. Not known

Col 55

37. Do you think your Child shows by his appearance that he is handicapped?

1. No
2. Yes
3. Other
4. Not known

Specify: e.g. big head, small head, etc.

Col 56

38. Who actually told you he was handicapped?

1. No one
2. Doctor (G.P. or Hospital)
3. Nurse/Health Visitor
4. Teacher/Psychologist
5. Social Worker
6. Neighbour/Relative
7. Other (specify)
8. Not known

Col 57

39. Where were you told?

1. Hospital
2. Home
3. Clinic (C.G.C. or Baby Clinic)
4. School
5. Street
6. Other
7. Not applicable
8. Not known

Col 58

40. Were you told in a satisfactory way?

1. No
2. Yes

Col 59

41. If NO to No. 40, was the deficiency in manner? or timing?

1. Unsympathetic
2. Too formal
3. Too emotional
4. Too late
5. Too soon
6. Not applicable (i.e. told satisfactorily on this count)
7. Not known

Col 60

42. If NO to No. 40, was the deficiency in content?

1. Too technical
2. Too much information
3. Too little information
4. Other
5. Not applicable (i.e. told satisfactorily)
6. Not known

Col 61

43. If NO to No. 40, was the deficiency in understandability?

1. Message not understood
2. Understood that child is handicapped but outlook unclear
3. Other
4. Not applicable (i.e. told satisfactorily)
5. Not known

PART III - PARENTS' REACTIONS AND PAST EXPERIENCES

Col 62

44. Father's predominant initial reaction to knowledge of child's handicap

Parents' perception (note verbatims)

1. Accepted as challenge
2. Accepted with resignation
3. Denied
4. Denied - sought other opinion
5. Blamed self
6. Blamed others
7. Other
8. Not known

Col 63

45. Mother's predominant initial reaction to knowledge of child's handicap

Parents' perception (note verbatims)

1. Accepted as challenge
2. Accepted with resignation
3. Denied
4. Denied - sought other opinion
5. Blamed self
6. Blamed others
7. Other
8. Not known

Col 64

46. Father's present reaction to knowledge of child's handicap

Parents' perception (note verbatims)

1. Accepts as challenge
2. Accepts with resignation
3. Denies
4. Denies - seeks other opinion
5. Blames self
6. Blames others
7. Other
8. Not known

Col 65

47. Mother's present reaction to knowledge of child's handicap

Parents' perception (note verbatims)

1. Accepts as challenge
2. Accepts with resignation
3. Denies
4. Denies - seeks other opinion
5. Blames self
6. Blames others
7. Other
8. Not known

Col 66

48. Father's relationship/attitude to child

Interviewers' judgment

1. Protective
2. Exclusive - ignores other children
3. Ambivalent - inconsistent
4. Rejecting
5. Withdrawn - mechanical attention to child
6. Accepting
7. Not known

Col 67

49. Mother's relationship/attitude to child

Interviewers' judgment

1. Protective
2. Exclusive - ignores other children
3. Ambivalent - inconsistent
4. Rejecting
5. Withdrawn - mechanical attention to child
6. Accepting
7. Not known

Col 68

50. General attitude of other close relatives of Father

1. Protective
2. Exclusive
3. Ambivalent
4. Rejecting
5. Withdrawn
6. Accepting
7. Not known

Col 69

51. General attitude of other close relatives of Mother

1. Protective
2. Exclusive
3. Ambivalent
4. Rejecting
5. Withdrawn
6. Accepting
7. Not known

Col 70

52. Is there any other relative living in the house?

Specify

1. No
2. Yes
3. Not known

Col 71

53. What effect on your other children has resulted from having this handicapped child at home?

1. No effect
2. Good effect on one
3. Good effect on all
4. Bad effect on one
5. Bad effect on all
6. Other
7. Not applicable
8. Not known

Col 72

54. Apart from initial information from which agency did you get most support?

1. Family Doctor
2. Hospital Doctor
3. Health Visitor/District Nurse
4. Social Worker
5. Voluntary Society
6. Teacher/Psychologist
7. Neighbour/Relative
8. Other
9. Not known

Col 73

55. From which agency did you mostly get information about services available?

1. Family Doctor
2. Hospital Doctor
3. Health Visitor/District Nurse
4. Social Worker
5. Voluntary Society
6. Teacher/Psychologist
7. Neighbour/Relative
8. Other
9. Not known

Col 74

56. Does Father subscribe to religious belief?

1. No
2. Church of Scotland
3. Church of England/Episcopal
4. Roman Catholic
5. Other Christian denomination
6. Non-Christian religion (Islam, etc.)
7. Other
8. Not known

Col 75

57. Does Mother subscribe to religious belief?

1. No
2. Church of Scotland
3. Church of England/Episcopal
4. Roman Catholic
5. Other Christian denomination
6. Non-Christian religion (Islam, etc.)
7. Other
8. Not known

Col 76

58. Needs met in the past - Counselling

1. No
2. Yes

Col 77

59. Needs met in the past - Support

1. No
2. Yes

Col 78

60. Needs met in the past - Playgroup/Nursery School

1. No
2. Yes

Identification Data

C A R D II

Cols 1 - 3

Interview Code No.

Col 4

61. Needs met in the past - Day Centre/Residential School

1. No
2. Yes

Col 5

62. Hospital

1. No
2. Under 3 months total stay
3. 3 - 6 months total stay
4. Over 6 months total stay

PART IV - PRESENT SITUATION AND NEEDS MET

Col 6

63. Housing

1. Owner-occupier
2. Rented flat/house or Tied property
3. Corporation/Council housing
4. Condemned property
5. Emergency housing
6. Not known

Col 7

64. Total family weekly Income

1. Less than £12
2. £12 - £19
3. £20 - £34
4. More than £35
5. Other
6. Not known

Col 8

65. Do you receive the Special Attendance Allowance in respect of the Child?

1. No
2. Yes

Col 9

66. Are you currently receiving any Counselling or Support?

1. No
2. Yes

Col 10

67. Child currently in Playgroup, Nursery School, Day Centre or Residential School?

1. No
2. Playgroup
3. Nursery School
4. Day Centre
5. Residential School
6. Other
7. Not known

Col 11

68. Child currently in Gogarburn Hospital?

1. No
2. Under 3 months
3. 3 - 6 months
4. Over 6 months
5. Other
6. Not known

Col 12

69. Child currently in Special School/Class or Junior Occupation Centre?

1. No
2. Special School
3. Special Class
4. Junior Occupation Centre
5. Other
6. Not known

Col 13

70. Have you received the services of a Home Help?

1. No
2. Local Authority Home Help
3. Private help
4. Other
5. Not known

Col 14

71. Baby-sitting available?

1. No
2. Yes and used
3. Yes not used
4. Other
5. Not known

Col 15

72. Present problems in caring for the child

1. Dental care
2. Hair cutting
3. Travel on 'buses
4. Place for child to play
5. Other - specify
6. Combinations of above - specify
7. No special problems
8. Not known

Col 16

73. Parents' perception of effect of handicapped child on marital relationship

1. Agree - brought us closer together
2. Agree - taken us further apart
3. Disagree
4. Unrateable
5. No change
6. Not known

Col 17

74. Father - effect on family size plans

1. No effect
2. No more children
3. Must have another to make up
4. Other
5. Not applicable
6. Not known

Col 18

75. Father - since this handicapped child was born have you spent more or less time at home?
1. No change
2. Less time
3. More time
4. Other/Not known

Col 19

76. If MORE or LESS in No. 75, Why?
1. Because of handicapped child
2. Other/Not known

Col 20

77. Father - since birth of handicapped child have you changed your job?
1. No
2. Yes
3. Other/Not known

Col 21

78. If YES in 77, Why?
1. Because of handicapped child
2. Other/Not known

Col 22

79. Father - since birth of handicapped child have you changed your hobbies or interests?
1. No
2. Yes
3. Other/Not known

Col 23

80. If YES in 79, Why?
1. Because of handicapped child
2. Other/Not known

Col 24

81. Mother - effect on family size plans
1. No effect
2. No more children
3. Must have another to make up
4. Other
5. Not known

Col 25

82. Mother - since birth of handicapped child has your social life been affected?
1. No change
2. Less social life
3. More social life
4. Other
5. Not known

Col 26

83. If MORE or LESS in 82, Why?
1. Because of handicapped child
2. Other/Not known

PART V - COPING, HOPES AND FEARS FOR FUTURE

Col 27

84. Parents' perception of how they are coping
1. Not well with stress
2. Not well without stress
3. Well with stress
4. Well without stress
5. Other
6. Not known

Col 28

85. Interviewers' perception of how parents are coping
1. Not well with stress
2. Not well without stress
3. Well with stress
4. Well without stress
5. Other
6. Not known

Col 29

86. What intervention would help parents most now
1. Hospitalization
2. Holiday admission
3. Counselling/support
4. Genetic counselling
5. Residential school
6. Shift to different school
7. Day Care Centre
8. Other
9. Not known

Col 30

87. Target in Child's education
1. Complete Special School
2. J.O.C. then S.T.C.
3. Transfer to ordinary school
4. Get "O" levels
5. Get "A" levels
6. Other
7. None envisaged
8. Not known

Col 31

88. What do you expect him to do when he grows up?
1. Nothing
2. I.T.U. or S.T.C.
3. Sheltered Workshop
4. Class V job
5. Class IV job
6. Class III job
7. Classes I - II profession
8. Other
9. Not known

Col 32

89. Would you want him to get married?
1. No
2. Yes
3. Other (including Disagreement)
4. Not known

Col 33

90. What does he need most now?
1. Nothing
2. Better/more medical care
3. Better/more teaching
4. Better/more nursing
5. Should go into hospital
6. Other (including speech therapy)
7. Not known

Col 34

91. Problems at present - incontinence
1. No
2. Wetting at night
3. Wetting day and night
4. Wetting and soiling day and night
5. Other
6. Not known

Col 35

92. Problems at present - overactivity
1. No
2. Very active by day
3. Active night and day
4. Never stops for a moment
5. Other
6. Not known

Col 36

93. Problems at present - eating problems
1. No
2. Eats very little
3. Has to be fed, etc.
4. Other
5. Not known

Col 37

94. Problems at present - food rituals/obsessions
1. No
2. Yes

Col 38

95. Problems at present - sleeping problem
1. No
2. Poor sleeper
3. Poor sleep plus screaming
4. Keeps or gets us up most nights
5. Other
6. Not known

Col 39

96. Problems at present - rocking/banging
1. No

Specify
2. Yes

Col 40

97. Problems at present - temper tantrums
1. No

Specify
2. Yes

Col 41

98. Main fear for the future
1. None
2. Not work
3. Not marry
4. Trouble with the police
5. People taking advantage of him
6. Other (parents dying first)
7. Not known

Col 42

99. Are you worried as to what will happen to him when you are dead
1. No
2. Yes

Col 43

100. Where would you wish him to live then
1. With relatives
2. With neighbours
3. Hostel
4. Hospital
5. Group home
6. Sheltered housing
7. Other
8. Not known

Col 44 - 46

Duration of Interview in minutes

Administered as above, the following details were ascertained by a careful reading of the verbatims, and programmed for the computer:-

Col 47

101. Marital status
1. First or subsequent marriage
2. Separated, divorced or widowed

Col 48

102. Index Child is Mongol
1. No
2. Yes

Col 49

103. Index Child is Only Son
1. No
2. Yes

Elicited from the authorities after the interviews were completed:-

Col 50

104. Psychologist's assessment in terms of proposed educational placement
1. More handicapped (J.O.C. etc.,)
2. Less handicapped (Special School/Class)
3. Not known to or known to but not tested by psychologist

Appendix B

A copy of the standardised letter sent to all the parents requesting the proposed interview

Dear Mr. and Mrs.

Your name has been given to us by (Edinburgh School Health Service or West Lothian Medical Officer of Health or the Physician Superintendent of Gogarburn Hospital) and we understand that you are agreeable to an interview in your own home.

Dr. Rebecca Wood and myself are conducting a survey into the needs and hopes of parents with handicapped children. In this we have the support of the education, health and welfare services, together with the parents' societies and voluntary agencies.

Dr. Wood has worked in America on an educational basis with mentally handicapped children. I am working with children and adults at Gogarburn Hospital and am particularly interested in stepping up the concern of the community in their care.

We would suggest (day, date, time) for our visit. If this date is not convenient we could come on (alternative date and time). We would be glad if you would return the slip in the envelope provided whether you require the date of the visit to be altered or not.

We hope very much to meet you in the near future.

With good wishes.

Yours sincerely,

G. F. Witcher

To: Mr. G. F. Witcher, Gogarburn Hospital, Edinburgh 12

1. ..... (day, date and time).....

*will be / will not be a suitable date and time for you to visit us.

2. ..... (day, date and time)..... would be convenient

3. Name and adress of family .....

* Please strike out whichever is inapplicable

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